

How do women under the care of eating disorder services experience sibling relationships : a phenomenological perspective

Jennifer Anne Smith

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## Abstract

### **Introduction**

Eating disorders are increasing in our society and prior research has considered the role of families, carers, partners and children in the development of these difficulties. Siblings, however, have been largely overlooked. The role of sibling relationships is not well understood, despite siblings being a long term, significant feature of many individuals with eating disorders' lives. This study aims to investigate the experiences of women with eating disorders and their sibling relationships.

### **Method**

Interpretative Phenomenological Analysis (IPA) was used to investigate the lived experiences of three women with diagnosed eating disorders. The women were interviewed, using a semi structured interview schedule designed for the study, and transcripts were analysed closely, following the principles of IPA.

### **Results**

Three superordinate themes were identified for each participant. These are 'Seeking Balance', 'Being Bad' and 'I Don't Correlate' for Amy, 'Not Being Noticed', 'Mealtimes are Stressful' and 'Everyone Runs Around After Her' for Jo and 'Being The Runt', 'Being Pushed Out' and 'Lost Identity' for Sarah. Four subthemes were also identified. These were 'Being Cut Off' for Amy, 'Being Pushed Out' and 'Shying Away' for Jo and 'Being Ridiculous' for Sarah.

## **Conclusion**

The sibling relationships in this sample were characterised by competition, rivalry, lack of understanding, conflict and distress. Many of the experiences shared were negative and were related as damaging to the individual. However, each relationship also contained strengths and all participants desired improved relationships and closeness with their siblings. Findings are discussed in terms of their implications for our current knowledge and further research.

### Statement of Contribution

The author was solely responsible for the following aspects of this work:

1. Obtaining ethical approval from IRAS, Lincoln University and Nottinghamshire Healthcare NHS Trust Research and Development Unit
2. Writing a review of the literature
3. Collecting the data
4. Analysing the data

The author, Dr Katherine Huke, clinical psychologist, Dr Caroline Bell, clinical psychologist and Johanna Mitchell, counselling psychologist were jointly involved in the design of the research.

Recruitment of participants was undertaken by clinicians from two Nottinghamshire Eating Disorder Services.

Clinical supervision for the project was provided to the author by Dr Katherine Huke, clinical psychologist and research supervision was received from Dr Mark Gresswell, Consultant Clinical Psychologist and Deputy Course Director.

Abstract

While much research has focussed on the experiences of carers and siblings of adults with eating disorders, there has been little focus on how those relationships are experienced by the person with the diagnosis. Research into the experience of sibling relationships has been especially sparse. Since sibling relationships are long lasting and qualitatively unique, this seems a strange omission. This study aims to investigate these relationships, using Interpretative Phenomenological Analysis (IPA). Three women with diagnosed eating disorders were interviewed about their sibling relationships. Three superordinate themes were identified for each participant. These are 'Seeking Balance', 'Being Bad' and 'I Don't Correlate' for Amy, 'Not Being Noticed', 'Mealtimes are Stressful' and 'Everyone Runs Around After Her' for Jo and 'Being The Runt', 'Being Pushed Out' and 'Lost Identity' for Sarah. Four subthemes were also identified. These were 'Being Cut Off' for Amy, 'Being Pushed Out' and 'Shying Away' for Jo and 'Being Ridiculous' for Sarah.

The significance of these themes to the individuals, and the current literature, limitations of the study and directions for further work are discussed.

## Introduction

### Eating Disorder Literature

Eating disorders have been increasing steadily over the last 100 years (Hoek, 2006), and the majority of individuals with a diagnosed eating disorder are thought to be women (Hoek, Bartelds, Bosveld, van der Graaf, Limpens, Maiwald, & Spaaij, 1995). In line with the increased frequency of diagnosis is the increased prominence of eating disorders within popular media, such as magazines and television. This suggests that there is a level of public interest in this area and that our culture is beginning to recognise the significance of these disorders. Eating disorders is the term commonly used to refer to a collection of difficulties and are often diagnosed as anorexia nervosa, bulimia nervosa and eating disorders not otherwise specified (EDNOS). Fairburn, Cooper & Shafran (2003) proposed the idea of the transdiagnostic model, which suggests that these labels are meaningless and support this with evidence that most individuals move between categories at different time points.

There have been many theories proposing possible causes of eating disorders, including genetics (Strober, Lampert, Morrell, Burroughs & Jacobs, 1990), psychoanalytic models (Dare & Crowther, 1995), family systems models (Eisler, 1993), sociocultural models (Gordon, 2000) and cognitive behavioural models (DeSilva, 1995). For a full description of these, please see the extended literature review. Other researchers, more recently, have noted the importance of control (Cooper & Fairburn, 2009; Wilson, Wilfley, Agras & Bryson, 2010) for individuals with eating disorders, and have investigated the role of avoidance



strategies within these disorders (Lampard, Byrne, McLean & Fursland, 2010; Rawal, Park & Williams, 2010).

### Caring for individuals with eating disorders

There has also been a recent interest in the experiences of caring for individuals with eating disorders, as the impact of these disorders is broad. Much research has been conducted to look into the experiences of carers and these studies have found that the carer burden is high, with significant effects on mental health and quality of life (Haigh & Treasure, 2003; Huke & Slade, 2006; Treasure, Szmulker, Todd, Gavan & Joyce, 2001). As a result of this evidence, rating scales have been developed and validated which can be used in clinical practice to assess this important area (Sepulveda, Whitney, Hankins & Treasure, 2008).

### Have sibling relationships been considered?

While the focus on carers develops to investigate the impact on parents, partners and children of individuals with eating disorders, the interest in siblings has only recently begun, though there have been a small number of studies considering this issue, which are discussed later in this review.

Cox (2010) has stated that the role of sibling relationships has been largely overlooked within family systems research, despite the fact that these relationships form part of the “complex, integrated, whole” described by Minuchin (1988). This is a strange omission for two reasons. Firstly, many people with eating disorders live in the family home with their parents, and other

siblings (Ratnasuriya, Eisler, Szmukler & Russell, 1991). Secondly, the literature investigating the importance of sibling relationships in other serious mental health problems, like schizophrenia, has been extensive and provided useful insights into the care and treatment of these problems. For example, Smith & Greenberg (2008) found that the quality of the sibling relationship significantly influenced the quality of life experienced by the individual with the diagnosis of schizophrenia. Liveley (1995) showed that siblings experience grief and loss, severe difficulties in maintaining their sibling relationship and a significant impact on their health, as a result of having a sibling with schizophrenia. Barak & Solomon (2005) demonstrated how important it is for services to be mindful of the siblings of individuals with schizophrenia, as they can experience their own significant mental health problems in response. It has also been demonstrated to be important in depression (Shaw, Dallos & Shoebridge, 2009) and autism spectrum disorder (Petalas, Hastings, Nash, Dowey & Reilly, 2009).

#### What is a sibling relationship?

Researchers have described the importance of sibling relationships:

“The sibling relationship is life’s longest lasting relationship, longer, for the most of us by a quarter of a century, than our ties to our parents. It lasts longer than our relationship with our children, certainly longer than with a spouse and, with the exception of a few lucky men and women, longer than with a best friend” (Bank & Kahn, 1997)

Though it could be argued that this description does not apply to all sibling relationships, it may be valid for many others. The description does not make any statements regarding the quality of the relationship, merely that it endures for a significant part of the individual's life. Therefore, the nature of these relationships may provide useful information for understanding human lived experience.

Sibling relationships have been traditionally viewed as sources of conflict and competition (Levy, 1937), and this can create problems for the family. Kramer & Baron (1995) assessed the views of parents with regard to the conflict of their children, and almost all reported that they believed their children "fight too much". However, this is a highly subjective and emotive subject. Many parents will feel that their children should not fight at all, others will feel they are not providing sufficient guidance or discipline if their children fight. Some parents may find it difficult to tolerate the noise and aggression of a sibling conflict and others may feel that the conflicts place a burden on them, as parents, to resolve and manage the conflict. However, it has been suggested that sibling conflict is a helpful method for learning social skills, conflict resolution and negotiation (Shantz & Hobart, 1989). Kramer (2010) highlights the need for future research to consider how sibling conflict could be best managed, to enhance conflict management skills, while protecting family harmony.

#### What impacts upon the sibling relationship?

There are any number of family factors, such as parental conflict (Poortman & Voorspotel, 2009), parental death (Khedyakov & Carr, 2009), childhood jealousy (Kelak & Volling, 2010) and birth order (Pollet & Nettle, 2009) which

have been shown to have an impact on sibling relationships. Parental divorce, however, was not shown to be a separate influence on the relationship, when parental conflict had been controlled for (Poortman & Voorspotel, 2009).

Related to the notion of childhood jealousy is Parental Differential Treatment (PDT). This has been investigated (McHale, Updegraff, Jackson-Newsom, Tucker & Crouter, 2000) as a possible mediator of sibling relationships. Their hypothesis is that children respond to each other more positively if their treatment from their parents is perceived as fair. Similarly, Sutor, Sechrist, Plikuhn, Pardo, Gilligan & Pillemer (2009) asked 708 adult siblings about their childhood perceptions of favouritism by their mothers and they found that this predicted the quality of the adult sibling relationship. It showed greater closeness between adult siblings who perceived their childhood parenting as 'fair'. This is, however, a difficult theory to evidence concretely, as those who recall their childhoods as 'fair' may be more likely to come from families who would be perceived as 'close' anyway.

Transitional stages into adulthood have also been found to impact upon sibling relationships, for example the impact of leaving home (White, 2001), completing education and becoming employed (Conley, 2004), and marriage and childbearing (Prentice, 2008) are all likely to alter and affect the sibling relationship, especially as most siblings go through these transitions at different times (Mouw, 2005). However, with the increased age of marriage and childbearing and the larger numbers of adult children remaining in the family home until the age of 30 and beyond (Jacob & Kleinert, 2008), it is not clear how these transitional stages currently affect sibling experiences.

Whiteman, Becerra & Killoren (2009) refer to a process of sibling deidentification. They state that this refers to a process of “consciously or unconsciously selecting different niches and developing different personal qualities in order to define themselves as unique or dissimilar from one another”. It has been proposed that the reason for this need to deidentify with one’s siblings is a protective strategy against comparison, rivalry and resentment (Feinberg & Hetherington, 2000; Schachter, Shore, Feldman-Rotman, Marquis & Campbell).

#### Existing studies of sibling relationships and people with eating disorders

Some studies have considered the importance of sibling relationships within the field of eating disorder research. For example, Dimitropoulos, Klopfer, Lazar & Schacter (2009) have also looked at sibling relationships from the perspective of the sibling. They asked 12 siblings of individuals with eating disorders for their perspectives on caring for their sisters. They used grounded theory to analyse their interviews and found six themes emerged. These themes were 1) sibling role as protector 2) family factors influencing sibling roles 3) consequences of AN on non-affected sibling 4) coping strategies 5) intentions of caregiving and 6) support systems. This indicates that the eating disorder does have a notable impact upon the life of the siblings. However, this study does not include information about how the relationship is perceived by the individual with the eating disorder. Other studies have been conducted to investigate this question (e.g. Bachner-Melman, 2005; Honey, Clarke, Halse, Kohn & Madden, 2006), but these have not been methodologically robust and have not provided sufficient information on the experienced relationship from the viewpoint of the

individual with an eating disorder. For a full description of these studies, please see the extended literature review.

It is clear that further work needs to be undertaken in the area of sibling experiences and eating disorders, with those that have been attempted focussing on the relationship from the sibling's perspective or have not been methodologically rigorous. Blessing (2007) raises the concern that siblings may be "the missing piece of the eating disorder puzzle", and yet there has been insufficient research to investigate their influence. The study proposed here will attempt to address some of the methodological issues seen in previous studies and provide information that may contribute to the development of theory in the future

### Aims

The aim of this study was to investigate the lived experience of women with eating disorders and their relationships with their siblings, in order to address this gap in the literature.

## Method

### Participants

Three women took part in this study. They had a mean age of 25 years (ranging from 21 to 30) and all were white British in origin. All were involved with the eating disorder services in Nottinghamshire and had received formal diagnoses from these services. Two participants were diagnosed with anorexia nervosa and one with bulimia nervosa. All three participants had at least one sister, participant 3 had two sisters and an absent step-brother with whom she had never had any relationship. Table 1, below, shows the demographic characteristics of the sample. Names contained within this table, and throughout the report, have been changed to protect anonymity.

Table 1: Demographic characteristics of participants

<b>'Name'</b>	<b>Ethnicity</b>	<b>Age</b>	<b>Brothers</b>	<b>Sisters</b>	<b>Birth order</b>	<b>Sibling age/s</b>
'Amy'	WB	24	0	1	Youngest	26
'Jo'	WB	21	0	1	Oldest	18
'Sarah'	WB	30	1(step)	2	Middle	26 & 33

### Recruitment

All three participants were recruited from the eating disorder services in Nottinghamshire, and were selected for the study by their treating clinicians. They were selected based on inclusion and exclusion criteria, which had been provided to the clinicians.

The inclusion criteria were as follows:

1. Female
2. Aged between 18 and 30
3. With one or two siblings

The exclusion criteria were as follows:

1. Unable to provide informed consent

These criteria were selected in order to try to ensure the participants had some common experiences, but without introducing significant recruitment difficulties. It was felt useful to limit the age range, as older participants may have greater difficulties in retrospectively discussing their experiences with their siblings, while these experiences may be more accessible for younger participants. It was also hypothesised that there could be significant experiential differences between being a sibling in a small family (2-3 children) and a sibling in a larger family (4 or more children). It is acknowledged that the participant age range of nine years (21 – 30), the different places in birth order, the different numbers of siblings and the age range of the siblings (18 – 33) has created a rather heterogeneous sample, however, this study was interested in finding the lived experiences of the individuals and has not sought to create a theory for application to broader groups.

Consent was required from all participants, so clinicians were also asked to select individuals who could give informed consent. Any participant who was experiencing perceptual disturbances, or high levels of emotional distress at the



time of recruitment, was not invited to participate. Clinicians were asked to make this decision, based on their knowledge of their client.

### Ethical Process

Ethical approval for this study was granted by Nottingham Research Ethics Committee 1 and by Lincoln University Ethics Committee in March 2010 (see Appendix J2 for a copy of all ethics correspondence).

### Interview Procedure

The researcher carried out three interviews at the therapy clinics in which the participants were treated. The interviews were digitally recorded, transcribed and analysed according to IPA principles. The interview schedule was designed to be open and non-directive, in order for the participant's own experiences to guide the process. The interview covered historical aspects of the sibling relationship, current aspects of the relationship and how the eating disorder has impacted upon the relationship (for a copy of the interview schedule, please see appendix E6).

### Analytic Procedure

The method of analysis chosen was Interpretative Phenomenological Analysis (IPA), which "is concerned with the detailed examination of human lived experience" and seeks to express that experience "in its own terms, rather than according to predefined category systems" (Smith, Flowers & Larkin, 2009). This appeared particularly relevant to this study, as the research question was concerned with the lived experiences of the sibling relationships, and, as an

exploratory study, there are no predefined category systems in which to categorise the data.

The analysis was undertaken following principles set out by Smith *et al.*, (2009), which requires that the researcher become familiar with the data through reading and re-reading of the transcript. During this process, notes were made which reflected the researcher's initial responses to the text. The next step requires that these initial comments be developed into "concise, pithy statements" (Smith *et al.*, 2009), which capture the essence of the meaning. These were then grouped together to form themes. A further process of refinement followed in which the themes were reviewed and superordinate themes were created. Throughout this process, the original interviews were continuously referenced, in order to ensure themes remained grounded in the participant's experiences. For a detailed account of the analytical process, see the extended method section.

### Validation Methods

This study is based on the interpretation of individual experiences, which is a core component of IPA (Smith *et al.*, 2009) therefore, it is necessary to ensure that the interpretations offered are valid and plausible when considered against the raw data. This study has achieved this through the presentation of data in a manner which allows transparency of process from raw data to superordinate themes. The process of supervision was also used to discuss emergent themes and consider alterations to these.

## Results

The themes which were identified from the text are as follows (NB: subthemes are in italics):

Amy	Jo	Sarah
Seeking Balance	Not Being Noticed	Being The Runt
Being Bad	<i>Being Pushed Out</i>	<i>Being Ridiculous</i>
I Don't Correlate	Mealtimes Are Stressful	Being Pushed Out
<i>Being Cut Off</i>	<i>Shying Away</i>	Lost Identity
Everyone Runs Around After Her		

I shall describe the themes for each participant individually and then provide some synthesis once their stories have been written. It should be noted that these concepts are discussed separately, but are, in reality, linked experiences.

### 'Amy'

#### 'Seeking Balance'

Amy's experiences of her relationship with her sister seem to be closely linked to comparing herself and her achievements to those of her older sister, seeking "balance" throughout. Amy felt that they were both concerned about being the risk of being viewed as similar, and both made deliberate attempts to create difference between their academic, social and family lives. Amy felt that she used to be seen as "the academic one", while her sister was "arty", but now, as a result of Amy's eating disorder, things have changed:

*“now she’s the one who’s... you know, I’m at a lower level in the kind of, you know, life success thing. I’m 24 and I live in my flat, and I don’t have a job, and I haven’t finished my university degree. And she’s in London, she’s done two degrees, she’s got a very long-term boyfriend in a flat, and she’s only... she’s 25, it’s kind of...”*

Her sense of being less successful than her sister is very powerful, both in the words she uses and her speech. She spoke more animatedly when she described her sister and tailed off, her voice disappearing at the end when she considered the impact this difference had on her.

The idea of ‘Balance’ is raised again when Amy discusses the role her eating disorder has played in her sibling relationship:

*“We’ve always been very different. But we’re kind of... erm. I’ve been quite, gone down the artistic-ish route, you know, Englishy stuff, and she’s gone down the business route, erm, into London and I suppose there was times when my academic success was more... You know, it had the potential to make things unequal, because she’s never been that academic. Always found that quite difficult. But we’ve made up for things in that... Kind of balance things out, don’t they? You know. Artsy girl, sciency girl. Erm. So we were in balance sort of then, but then, when I had quite a severe eating disorder, and she was quite healthy, it still stayed in balance because I had something and she had something”*

It appears here that Amy is providing some explanation for the function of her eating disorder and without this, she would be vulnerable to being compared

unfavourably to her successful sister. For further consideration of this theme, please see the extended results section.

### 'Being Bad'

Amy's speech was littered with references to herself as a damaging, toxic influence within the family. She believes her eating disorder has contributed to the problems in her relationship with her sister and has caused distress and physical illness to her parents:

*"And my dad does get very stressed and my mum was very emotional. And my sister felt very resentful to me about that"*

She stated that "I've damaged the family, I think". Amy believes that this damage is so severe, and so unavoidable, that she has concluded that it is in their best interests for her to live alone, away from her family, in order to protect them from the distress she brings:

*"Because they're happier, and I see that they're happier. Well, everyone does really.....And that's because I'm not there, so that's a good thing".*

Amy also views herself as the "bad" sibling, while her sister is the "good" and the "innocent" one.

### 'I Don't Correlate'

Amy's experience of herself and her family have led her to the conclusion that she doesn't fit with others and that she did not "correlate with the world". This sense of disconnection from others was so powerful it meant that she no longer even felt she belonged in a "human reality" and that she had "departed from the

world". She believed that her sister was using harsh language to try to re-engage her with people:

*"She wanted me back in the real world, which I had departed I think....I think she just wanted to shock me back into reality and to say "look in the mirror, you look disgusting""*.

This theme contains the subtheme of 'Being Cut Off', which is outlined in detail in the extended results section. It refers to her feelings of being "detached", both physically and emotionally, from the world around her. Some of this has happened as a result of her eating disorder, but she also believes that she has made deliberate attempts to isolate herself from others, as a defence.

## **Jo**

### **'Never Being Noticed'**

Jo's experiences with her younger sister have left her with a powerful feeling of being entirely unable to be noticed, praised or appreciated. Jo is "vying for attention" from her mother primarily, with a sister who is described as equally determined to hold their parents' attention. Jo reported that her younger sister had always been "prone to tantrums" and that her family had always "given in", to minimise the stress. Jo stated that:

*"No matter what I did, I didn't get noticed"*

This was experienced by Jo as painful and she described a process of realising, through her therapy, that

*“not eating was my way of trying to get noticed and trying to get a bit of attention if you like. Like my cry for help”.*

Jo’s perception of her sister is that she was seen as the “favourite” in the family, but she acknowledges that her sister had the opposite view. There is a strong sense that each sister is equally uncertain of their place in the family:

*“We’d always sort of feel that no matter what happened, it was always the other one that was the favourite”*

And while her sister was able to “shout out to get attention”, Jo did not feel comfortable with this, and looked to other strategies, such as restricting her food intake.

This theme contains the subtheme of ‘Being Pushed Out’, which is discussed in the extended results section. This theme relates to her belief that her family have chosen to favour her sister, and that she is deliberately excluded from their activities.

#### ‘Stressful Mealtimes’

The level of conflict between Jo and her sister was very high. There were verbal arguments and physical fights, and these often occurred around mealtimes:

*“And so it was always stress at teatime ‘cos they were busy and she was busy and then (sister) would always kick off that I’d come in and interrupted tea and I wanted to be the centre of attention, when in reality, I had just come in and dumped my bags and just wanted to say Hi really. But I suppose*

*mealtimes were always quite stressful at home. (Sister) was a picky eater. She won't eat pork because she likes Piglet from Winnie the Pooh and loads of little daft things. Mealtimes were always stressful".*

Jo explicitly states that mealtimes are stressful three times in this paragraph, placing significant emphasis on this concept.

Jo would then leave, to end the conflict:

*"I'd end up sitting in the room on my own, waiting, just to stay out of the way and save confrontation. And then I'd end up eating on my own afterwards".*

Thus the conflict is undesirable, and seems to lead to Jo being isolated.

Throughout the text, she makes many references to this high level of conflict between herself and her sister, which are discussed further in the extended results section. The associated subtheme, 'Shying Away' is also discussed. This relates to her level of unhappiness with the high levels of conflict and her associated need to make attempts to avoid it.

#### 'Everyone Runs Around After Her'

Jo describes her sister's behaviour and position in the family with a significant amount of jealousy and resentment.

Jo seems to be feeling resentment when she talks about how her family respond to her sister's behaviour:



*"It just seems, even though she's my younger sister, it just seems sort of she's got everyone running rings around her. She's always been the one that's in control"*

She feels that she has been treated unfairly, here describing an incident on a family holiday in which her sister's choice is picked over her own:

*"The one thing I wanted to do was go in the Disney Castle.....and we only had an hour left and (sister) stood there and she kicked and she screamed because she wanted to go back on this rollercoaster that we'd been on sort of three or four times already. And, you know, we went on this rollercoaster and I didn't get to go in the castle"*

Later, Jo describes how her sister was rewarded for eating at mealtimes, as a result of being a "picky eater". During this comment, the tone of her voice was angry and she placed the verbal emphasis on "I", to demonstrate how she felt about this:

*"There would be some sort of reward if you like. She actually had a sticker chart.....I never had a sticker chart"*

Jo's memory is of being treated unfairly, as she stated that she always ate her food as a child. She feels that she was not rewarded for this, and it was never remarked upon, but her sister, who controlled mealtimes with her "demands" for foods she liked and her refusal to eat, was rewarded and praised. She explained that this left her feeling "frustrated", "angry" and "upset".

This theme is further explained in the extended results.

## **Sarah**

### **'Being The Runt'**

Sarah described one theme which ran through most of her speech about her experiences with her sisters, and this was the deeply held belief that she is somehow defective, or “the disappointment” and “evil and nasty”. Her discourse was littered with examples of words such as “let down”, “runt”, “bad”, “spiteful” and “everything is my fault”, which she was using to describe how she felt about herself, as well as her perception of how her family felt about her. Her belief that she has so many “flaws” is so strongly held that she explains that this is the reason she does not have a close, personal bond with her sisters:

*“I don’t want them to know the real me, because I don’t want them to not like me. Even though, as a result, I have pushed them away really”.*

The subtheme linked to this is the idea of ‘Being Ridiculous’. Sarah described a great deal of criticism from her younger sister, regarding her body shape, her exercise habits and her diet. This criticism was also extended to her choice of profession and her relationship with their mother. For a discussion of this theme, please see the extended results.

### **'Being Pushed Out'**

Sarah has created a powerful, visual image, of her perceived exclusion:

*“I was only the one that didn’t have a hand to hold, when we went anywhere. I don’t think it was deliberate, looking back. I don’t suppose I’d ever*

*think about it much at the time, where I were little, but I felt lonely. I didn't feel like I was the same as my sisters"*

This demonstrates her feeling of being literally overlooked. The image of the family walking together, with each parent holding the hand of a child, while she walks separately from them is quite moving.

### 'Lost Identity'

Sarah describes her feelings of being unable to find a separate identity for herself:

*"(Younger sister) was the baby, (older sister) could have a free rein.. but for the first five years of my life I was dressed the same as my eldest sister.....and then my youngest sister was wearing the same clothes as me, up until I was 11 or 12. So I didn't really have an identity. That's how I felt".*

This was also linked to her belief that her father had wanted a son:

*"Dad had never had a boy and he always wanted a son, so I think I tried to take on that role, tried to be a bit more tomboyish for him really.....but that's not really me, because I'm quite girly".*

This theme is discussed more fully in the extended results section.

### Synthesis

With a heterogeneous sample, it is difficult to draw too many comparisons, however, there were some areas of commonality between Amy, Jo and Sarah's experiences. They each described feelings of being excluded, or cut off, from

their families. These feelings had their origins in childhood memories, but seemed to have been compounded by their eating problems and the relationship difficulties with their sisters. Also, there was some indication that the three women all had some hope that their relationships with their sisters might become closer:

For example, Sarah describes a very powerful feeling of desperately wanting to communicate openly with her sisters:

*“They don’t know. I want to scream at them, say well you haven’t got – you know, they haven’t got a clue how I feel and that I don’t want to have anything else going on in my life at the moment”*

For Jo, the longing for closeness may be demonstrated by her transferral of all her need for support to her boyfriend:

*“It was always sort of real sort of gentle, like we’d be sitting and he’d be eating, and he’d try and encourage me to eat and if, you know, if I had like a tiny bite of his pizza, he’d make a big fuss of me and... so I suppose, whereas I didn’t get any attention from my parents, I was getting it from him”*

Amy demonstrated that she had been thinking about her relationship with her sister, and how she would like it to improve over time:

*“And I’m kind of hoping that eventually it’ll come back into something like.... I can’t say normality but, being close I suppose. Sometimes I wonder if my parents will have to die for that to happen”*

In summary, the themes identified encompassed a complex range of emotional relationships, linked closely to experiences with parents. The large majority of the relationship was experienced as a struggle with comparisons, feeling excluded, conflict and self dislike, but all had some experiences of wanting improved relationships.

### Discussion

This study used a qualitative approach to identify the way in which women with eating disorders experience their relationships with their siblings. The themes identified were as follows: 'Seeking Balance', 'Being Bad' and 'I Don't Correlate' for Amy, 'Not Being Noticed', 'Mealtimes are Stressful' and 'Everyone Runs Around After Her' for Jo and 'Being The Runt', 'Being Pushed Out' and 'Lost Identity' for Sarah. Four subthemes were also identified. These were 'Being Cut Off' for Amy, 'Being Pushed Out' and 'Shying Away' for Jo and 'Being Ridiculous' for Sarah.

### How do the findings link to the literature?

Though this study is not seeking to support or refute any theory, it is interesting to consider where the data makes links with existing ideas.

### Deidentification

Prior research has talked about the concept of deidentifying with siblings (Schachter, Shore, Feldman-Rotman, Marquis & Campbell, 1976; Whiteman, Becerra & Killoren, 2009). It has been proposed that this is a process in which siblings attempt to mark out their own identities and delineate a 'separateness' between themselves and their siblings. It has been observed to occur more

markedly in siblings of the same gender, who are less than two years apart in age (Schachter *et al.*, 1976) and the proposed reason for this process is that it is a protective strategy against comparison, rivalry and resentment (Feinberg & Hetherington, 2000).

Two of the participants in this study, Amy and Sarah, provided some indication that they were involved in this process. Amy explicitly stated that she and her sister, who were only 18 months apart in age, may have made deliberate attempts to define themselves as separately as possible. She also explicitly described this as a protective strategy, to reduce comparison and provide protection against either being seen as the less successful sister. Sarah also talked about ideas of identity, which could be linked to this process. She described the feeling of having 'lost' her own identity through, what she perceived to be, excessive similarity between herself and her sisters. However, it should be noted that this similarity appears to have been created by the requirement for them to share clothes and may not have been present without this. Indeed, Sarah does also describe herself as very different from her sisters; whom she views as 'perfect' and 'lovely' while describing herself as 'the runt'. It could also be hypothesised that Sarah's change of career may have been an attempt to deidentify from her sister, who shared that career, but this was not discussed in the interview and no data arose to indicate this. Jo, who was three years older than her sister, did not describe any processes of deidentification. This may be the cause or consequence of viewing herself as very different from her sister. She described the long term family narrative of she and her sister

'always' being very different. This, or the slightly larger age gap between them, may have protected her from the need to deidentify.

### Parental Differential Treatment

McHale, Updegraff, Jackson-Newsom, Tucker & Crouter (2000), have investigated the idea that siblings relate more positively to each other when their parents treat them 'fairly', as opposed to 'equally'.

Jo made frequent references to the differences between her and her sister, and placed them in the context of the differences in the ways they were treated by their parents. Jo appeared to feel that she was overlooked and her accomplishments ignored because she was 'quiet', while their family spent much time placating and appeasing her sister. Her sense that this was unfair was emphasised when she described how their mother repeatedly prioritised her younger daughter's relationship problems over Jo's recent diagnosis of an eating disorder. Jo also appeared to feel that this perceived unfairness had contributed to the difficulties in her relationship with her sister. Sarah and Amy appeared to focus far less on the differences in parental approaches to themselves and their sisters. Indeed, Amy's perspective seems to be that she created all of her own problems and, in doing so, has added considerably to those of her whole family, including her sister. She did not suggest any feelings of having been unfairly treated by their parents. Sarah did provide some indication that this may have been a relevant process for her. She explained that there have been occasions when she has observed her sisters being

praised and rewarded for achievements, which Sarah feels have been unnoticed in her. She also appeared to be unhappy that on each occasion there was a need for one of the children to move out of the family home, it was she who was expected to go. Interestingly, she did not appear to be reassured by the explanations given for this choice, despite stating that she understood them. This might imply that she did, in fact, view the decision as fair, but continued to feel hurt by the different treatment she received.

### The impact of conflict

Kramer (2010) suggested that there may be an 'optimum' level of conflict between siblings; with too much conflict creating intolerable levels of distress and damaging the relationship, or even preventing a relationship from forming, and too little reducing the opportunity for children to learn conflict management and negotiation skills.

Jo reported the highest levels of conflict between her and her sister. She described verbal and physical confrontations, often, though not exclusively, focussed around mealtimes, which seemed to have created 'flashpoints' for the sisters. Although she described herself as the 'quieter' sister, Jo acknowledged that she actively participated in this conflict. She reported very little experience of spending time with her sister without conflict of some sort and she felt that this had damaged their relationship significantly. Amy and Sarah reported very little conflict with their sisters. Amy described some experience of her sister becoming angry with her during her first admission to hospital as a result of her very low body weight, but did not indicate that she responded to this anger at all. In many ways, she seemed to share her sister's view that she was indeed



‘disgusting’. Similarly, Sarah had some experience of her younger sister becoming angry with her over her exercise habits but, again, did not indicate that she responded to this anger and, again, appeared to agree that she was being ‘ridiculous’. Though it should be noted that the process of an IPA interview is, by necessity, participant led. As such, it may be that there are examples of conflict between Amy, Sarah and their sisters which were not discussed. However, the main difference here appears to be that Jo’s experience of conflict with her sister stretches back into early childhood, while Amy and Sarah only described examples which were apparently motivated by their sister’s distress regarding the eating disorders and associated behaviours, which developed in adolescence.

### Family Systems Model

Eisler (1993) explains that the causality of EDs is circular, not linear, in that it develops within the context of a family relationship and also becomes a part of that relationship. The participants’ relationships with their siblings were heavily moderated by their interactions with their families as a whole. The ideas relating to comparisons, identity, being pushed out and being different were all very closely tied to experiences with parents in general, and mothers in particular. For example, Jo appeared to feel that she and her sister were competing for their mother’s attention, and she believed that this drove the intense rivalry between them. Amy’s difficulties with her sister were closely linked to the feelings of her parents and the sister’s concern for those parents. Sarah’s sisters were both seen as favoured and perceived to receive more support and encouragement from their mother.

Sibling relationships are not chosen, they are decided by birth, and they might endure for longer than any other relationship (Bank & Kahn, 1997). If the relationship is experienced as threatening or hostile, this creates a long term bond with someone who has the potential to be emotionally, or physically, damaging. But the individual is also aware that family ties are important, and feels compelled to try to improve the relationship. For example, Jo, comments on this directly. This is set in the context of a family, with parental expectation and emotional consequences. If one's children cannot tolerate each other, this may be experienced as a reflection of one's own parenting. This may increase the need to resolve the difficulty, which could add pressure to the already fraught relationship.

The only previous study which has looked at the experience of the relationship from the perspective of the sibling with an eating disorder was Bachner-Melman (2005). This study did not identify specific themes, but rather summarised interviews with the participants. It is difficult to draw direct comparisons between this study and Bachner-Melman's work as the samples in both studies are heterogenous, however, all participants were women with diagnosed eating disorders. Bachner-Melman identified that 'distance, antagonism and rivalry' were the main experiences of the participants and their siblings. She also noted that they did not feel that they belonged with their families, which may map onto the themes identified here, of 'I Don't Correlate' (Amy), 'Not Being Noticed' (Jo) and 'Being Pushed Out' (Sarah). Bachner-Melman also noted that her participants all experienced a "strong, compensatory need to belong". This could link to the subtheme identified here of 'longing for closeness'. She

concluded that “feeling emotionally isolated from, and misunderstood by siblings may be a predisposing factor in the development of AN, just as feeling basically accepted and understood by them may be protective”. During the current study, one participant, Jo, made direct links between the relationship difficulties with her sister and the development of her eating problems. The current study has one strength as compared to the Bachner-Melman (2005) study in that it sought to analyse the data using a known qualitative method, which is open to replication. Though it suffers equally from the difficulties associated with a small, heterogenous, sample.

#### The advantages of IPA studies

Interpretative Phenomenological Analysis (IPA) aims to investigate how people make sense of their experiences and, as such, it is a very useful tool for trying to discover how something has been perceived, or ‘what it is like’ for that person. The theoretical underpinning of IPA is based on philosophers such as Heidegger (among others), who believed that all knowledge is subject to interpretation and experiences can only be meaningfully understood in the context of that interpretation (Heidegger, 1962). This basis makes IPA a very useful method of trying to understand how a person experiences a relationship. It would be possible, though challenging, to investigate the quality and experience of a relationship through empirical means, such as rating scales, for example. This approach might, with carefully constructed questioning, yield some numerical figures which could be used to provide some quantitative statements about the relationship. However, there would be many problems with this approach. Firstly, it would probably require large numbers of questions

to capture the different aspects of the relationship in this format. Secondly, it is arguable that a reductionist approach to something as broadly defined as a 'relationship' might miss a large pool of data. Thirdly, though it might be easy to administer a questionnaire to large numbers of people, it is difficult to say whether one person's rating of 'closeness', for example, matches up with another. Person A might believe a rating of four, on a scale of one to ten, equates to very little closeness, while Person B might think rating of five or six expresses the same amount. Equally, there would be difficulties associated with the interpretation of what 'closeness' means to different people. However, the most significant difficulty which would be faced would be the problem of the researcher pre-determining which 'relationship factors' should be included and studied. A researcher with a history of working with clients with eating disorders might have clear expectations of which traits to include, based on their clinical experience. Similarly, a researcher with little experience of eating disorders might focus their item selection on factors which could be equally irrelevant to the participants' actual experiences. Any methodology which seeks to understand what something is like, should aim to ensure that it is not imposing an external structure of pre-determined categories, or it risks smothering important, unexpected data with less relevant information.

IPA offers a framework which can answer the possible difficulties outlined above. IPA studies can be undertaken with any number of participants, though it is important to ensure all data can be analysed in sufficient detail so it is not recommended to generate an excess of data. Meaningful results can be obtained from small samples. IPA also seeks to consider experience in its own

terms, it does not seek to reduce it to smaller components. For example, a questionnaire study might ask a participant to rate how frequently they argue with their sibling, which would provide a numerical score, but it demonstrates nothing about how that conflict is experienced, how relevant it is perceived to be and how it fits into the context of that person's overall relationship. IPA places the experience into those contexts.

IPA also allows the researcher to investigate the meaning of individual words or sentences, to consider the language used and the tone of voice, but it also ensures that the coherent narrative is retained. The researcher is not presenting their own interpretation of the person's experiences without continued reference back to the actual words used. This enables the narrative to emerge, alongside the detailed analysis.

In areas where there is limited knowledge or pre-existing theory, IPA is very useful to explore the experiences. This in itself has enormous value, but it can also be used to build theories which can be subjected to larger scale investigation in future studies,

IPA is idiographic, in that it is based upon the experiences of the person being interviewed, and how they perceived those experiences. This means that the interview is flexible and is largely controlled by the participant. The researcher does not dictate which aspects can be discussed. This means that the themes identified are more likely to be based on the actual experiences of the participant rather than the preconceived theory of the researcher.

### What are the implications of this study?

Clinically, the findings of this study can be translated into the therapy setting. It has been shown that insufficient attention has been paid to sibling relationships in the development of theories, and in clinical practice (Blessing, 2007). This study highlights the importance of routinely assessing the quality of sibling relationships with clients who have siblings, and considering these in the context of the themes identified. It may be useful to develop a specific assessment tool, to consider the quality of the sibling relationship, alongside the relationships with parents, during the assessment phase of treatment for eating disorders. Such a tool could be linked to an overarching assessment of family relationships, to fit the family systems model. Also, the themes and subthemes identified within this study could be considered during assessment and treatment.

This study has highlighted the need to consider feelings of insignificance and unmet needs for closeness and understanding. While these needs could be met within the therapeutic relationship, consideration should be given to how the family can develop these. Finally, while sibling relationships do appear to be significant for women with eating disorders, these relationships are always contextualised by the role of the parents. This provides support for the clinical treatment of eating disorders using a family therapy approach.

Further research into this area could usefully begin to assess whether these themes endure in larger samples, and whether sibling dyads have shared experiences of their relationships. Current research has focussed on the

relationship from one perspective or the other and it may well be very useful to investigate how sibling dyads experience each other. A further study could also investigate whether the experience of having brothers is qualitatively different to that of having sisters.

#### Limitations of this study

This study has a small sample size, which, though acceptable within IPA, is not in the ideal range. This may mean that the themes identified here are less relevant for other women with eating disorders and their siblings. However, as IPA is primarily concerned with the lived experiences of individuals, this is less of a concern. The sample shared some features, such as gender and sibling gender, but number of siblings, age range, birth order and age range of siblings were varied. This suggests that the sample was not homogenous, which meant that comparisons could not safely be made across participants.

Other limitations include the fact that the participants were all at different stages of their therapy and may have had more or less time to consider their relationships with their siblings as related to their eating disorders. Finally, the participants for this study were selected by clinicians, but it is not clear whether those who chose to participate differed from those who declined. It may be that only those who experienced their sibling relationships as particularly distressing chose to participate, while those who fitted the criteria but had more positive experiences may have felt they had less reason to participate. For a further discussion of the limitations of this study, please see the extended discussion.

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## Appendices

### Appendix 1 - Journal Guidelines

#### **European Eating Disorders Review**

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#### **Author Guidelines**

##### **Manuscript Submission**

European Eating Disorders Review has now adopted ScholarOne Manuscripts, for online manuscript submission and peer review. The new system brings with it a whole host of benefits including:

- Quick and easy submission
- Administration centralised and reduced
- Significant decrease in peer review times

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**Illustrations** must be submitted in electronic format. Save each figure as a separate file, in **TIFF** or **EPS** format preferably, and include the source file. We favour dedicated illustration packages over tools such as Excel or Powerpoint. Grey shading (tints) are not acceptable. Lettering must be of a reasonable size that would still be clearly legible upon reduction, and consistent within each figure and set of figures. Supply artwork at the intended size for printing. The

artwork must be sized to the text width of 7 cm (single column) or 15 cm (double column).

**Manuscript style.** The language of the journal is English. All submissions including book reviews, must have a title, be printed on one side of the paper, be double-line spaced and have a margin of 3cm all round. Illustrations and tables must be printed on separate sheets, and not be incorporated into the text.

- The **title page** must list the full title, short title of up to 70 characters and names and affiliations of all authors. Give the full address, including e-mail, telephone and fax, of the author who is to check the proofs.
- Include the name(s) of any **sponsor(s)** of the research contained in the paper, along with **grant number(s)** .
- Supply an **abstract** of up to 150 words for all articles [except book reviews]. An abstract is a concise summary of the whole paper, not just the conclusions, and is understandable without reference to the rest of the paper. It should contain no citation to other published work.
- Include up to five **keywords** that describe your paper for indexing purposes.

**Reference style** . The APA system of citing sources indicates the author's last name and the date, in parentheses, within the text of the paper.

**A. A typical citation of an entire work consists of the author's name and the year of publication .**

Example: Charlotte and Emily Bronte were polar opposites, not only in their personalities but in their sources of inspiration for writing (Taylor, 1990). Use the last name only in both first and subsequent citations, except when there is more than one author with the same last name. In that case, use the last name and the first initial.

**B. If the author is named in the text, only the year is cited .**

Example: According to Irene Taylor (1990), the personalities of Charlotte. . .

**C. If both the name of the author and the date are used in the text, parenthetical reference is not necessary .**

Example: In a 1989 article, Gould explains Darwin's most successful. . .

**D. Specific citations of pages or chapters follow the year .**

Example: Emily Bronte "expressed increasing hostility for the world of human relationships, whether sexual or social" (Taylor, 1988, p. 11).

**E. When the reference is to a work by two authors, cite both names each time the reference appears .**

Example: Sexual-selection theory often has been used to explore patterns of various insect matings (Alcock & Thornhill, 1983) . . . Alcock and Thornhill (1983) also demonstrate. . .

**F. When the reference is to a work by three to five authors, cite all the authors the first time the reference appears. In a subsequent reference, use the first author's last name followed by *et al* . (meaning "and others") .**

Example: Patterns of byzantine intrigue have long plagued the internal politics of community college administration in Texas (Douglas *et al* ., 1997) When the reference is to a work by six or more authors, use only the first author's name followed by *et al* . in the first and all subsequent references. The only exceptions to this rule are when some confusion might result because of similar names or the same author being cited. In that case, cite enough authors so that the distinction is clear.

**G. When the reference is to a work by a corporate author, use the name of the organization as the author .**

Example: Retired officers retain access to all of the university's educational and recreational facilities (Columbia University, 1987, p. 54).

**H. Personal letters, telephone calls, and other material that cannot be retrieved are not listed in References but are cited in the text .**

Example: Jesse Moore (telephone conversation, April 17, 1989) confirmed that the ideas. . .

**I. Parenthetical references may mention more than one work, particularly when ideas have been summarized after drawing from several sources. Multiple citations should be arranged as follows .**

Examples:

- List two or more works by the same author in order of the date of publication: (Gould, 1987, 1989)
- Differentiate works by the same author and with the same publication date by adding an identifying letter to each date: (Bloom, 1987a, 1987b)
- List works by different authors in alphabetical order by last name, and use semicolons to separate the references: (Gould, 1989; Smith, 1983; Tutwiler, 1989).

All references must be complete and accurate. Where possible the DOI for the reference should be included at the end of the reference. Online citations should include date of access. If necessary, cite unpublished or personal work in the text but do not include it in the reference list. References should be listed in the following style:

### **Journal Article**



Gardikiotis, A., Martin, R., & Hewstone, M. (2004). The representation of majorities and minorities in the British press: A content analytic approach. *European Journal of Social Psychology*, 34 , 637-646. DOI: 10.1002/ejsp.221

### **Book**

Paloutzian, R. F. (1996). *Invitation to the psychology of religion* (2nd ed.). Boston: Allyn and Bacon.

### **Book with More than One Author**

Natarajan, R., & Chaturvedi, R. (1983). *Geology of the Indian Ocean* . Hartford, CT: University of Hartford Press.  
Hesen, J., Carpenter, K., Moriber, H., & Milsop, A. (1983). *Computers in the business world* . Hartford, CT: Capital Press. and so on.  
The abbreviation *et al.* is not used in the reference list, regardless of the number of authors, although it can be used in the text citation of material with three to five authors (after the initial citation, when all are listed) and in all parenthetical citations of material with six or more authors.

### **Web Document on University Program or Department Web Site**

Degelman, D., & Harris, M. L. (2000). *APA style essentials* . Retrieved May 18, 2000, from Vanguard University, Department of Psychology Website: [http://www.vanguard.edu/faculty/ddegelman/index.cfm?doc\\_id=796](http://www.vanguard.edu/faculty/ddegelman/index.cfm?doc_id=796)

### **Stand-alone Web Document (no date)**

Nielsen, M. E. (n.d.). *Notable people in psychology of religion* . Retrieved August 3, 2001, from <http://www.psywww.com/psyrelig/psyrelpr.htm>

### **Journal Article from Database**

Hien, D., & Honeyman, T. (2000). A closer look at the drug abuse-maternal aggression link. *Journal of Interpersonal Violence*, 15 , 503-522. Retrieved May 20, 2000, from ProQuest database.

### **Abstract from Secondary Database**

Garrity, K., & Degelman, D. (1990). Effect of server introduction on restaurant tipping. *Journal of Applied Social Psychology*, 20 , 168-172. Abstract retrieved July 23, 2001, from PsycINFO database.

### **Article or Chapter in an Edited Book**

Shea, J. D. (1992). Religion and sexual adjustment. In J. F. Schumaker (Ed.), *Religion and mental health* (pp. 70-84). New York: Oxford University Press.

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## Appendix 2 – Ethical Approval Correspondence

### 1. Initial ethical approval letter

**NHS**  
**National Research Ethics Service**  
Nottingham Research Ethics Committee 1  
1 Standard Court  
Park Row  
Nottingham  
NG1 6GN  
Telephone: 01158839425  
Facsimile: 01150129300

17 March 2010

Miss Jennifer Smith  
Trainee Clinical Psychologist  
Lincolnshire Partnership Foundation NHS Trust  
Court 11, Satellite Building 8  
University of Lincoln  
Brayford Pool, Lincoln  
LN6 7TS

Dear Miss Smith

**Study Title:** How do women under the care of eating disorder services experience sibling relationships: a phenomenological perspective.

**REC reference number:** 10/H0403/17

**Protocol number:** 4

Thank you for your letter of 04 March 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

**Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

**Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

This Research Ethics Committee is an advisory committee to East Midlands Strategic Health Authority. The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England.

*Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

*Sponsors are not required to notify the Committee of approvals from host organisations.*

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
REC application	42266/91393/1/23	19 January 2010
Protocol	4	13 January 2010
Investigator CV		20 January 2010
Participant Consent Form	3	27 January 2010
Interview Schedules/Topic Guides		
Academic supervisor CV		
Participant Information Sheet	5	02 March 2010
Response to Request for Further Information		04 March 2010

#### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### **After ethical review**

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document 'After ethical review – guidance for researchers' gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).



10/H0403/17

Please quote this number on all correspondence

Yours sincerely



**Dr K Pointon**  
**Chair**

Email: [trish.wheat@nottspct.nhs.uk](mailto:trish.wheat@nottspct.nhs.uk)

Enclosures: "After ethical review – guidance for researchers"

Copy to:

Dr Mark Gresswell  
University of Lincoln  
Court 11, satellite building 8  
Brayford pool  
Lincoln, LN6 7TS

R&D Department for NHS care organisation at lead site- Nottinghamshire Healthcare NHS Trust

## 2. Request for minor amendment

- **RE: Study ref: 10/H0403/17**

To Jenny Smith

From: **Wheat Trish - Administrator - NctPCT** (Trish.Wheat@nottspct.nhs.uk)

Sent: 18 May 2010 09:35:51

To: Jenny Smith (jenny\_anne\_smith@hotmail.com)

Dear Jenny

Sorry I have not got back to you - I have been out of the office quite a lot recently and no one else accesses my emails.

Dr Pointon has said it is o.k. to approve your request as a minor amendment (both points). Before I do so, will the changes affect any wording in any documents e.g. the study protocol, participant information sheet etc.? If so, can you send any revised documents by email, and then I will action the amendment letter.

Best Wishes

Trish

Ms Trish Wheat | [Committee Coordinator](#)


[Nottingham Research Ethics Committee 1](#)

[Direct line 0115 8839390 | Switchboard 0115 8839530](#)

[1 Standard Court, Park Row, Nottingham, NG1 6GN](#)

[Email: trish.wheat@nottspct.nhs.uk | www.nres.npsa.nhs.uk](#)

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**From:** Jenny Smith [mailto:jenny\_anne\_smith@hotmail.com]  
**Sent:** 17 May 2010 12:15  
**To:** Wheat Trish - Administrator - NCTPCT  
**Subject:** RE: Study ref: 10/H0403/17

Trish

Hi. I am still waiting for a reply to my query. This is beginning to cause a serious problem, as the deadline for completion of my thesis is 30th July. I cannot collect data while I'm waiting for the query to be answered, and, as you can appreciate, myself and my supervisors are becoming increasingly anxious. The query should not constitute a major amendment, and as such, should have been relatively straightforward to answer.

I would appreciate a response as soon as possible please, as I need to take this forward as a matter of increasing urgency!

Many thanks for your help,

Jenny Smith

---

From: jenny\_anne\_smith@hotmail.com  
To: trish.wheat@nottspct.nhs.uk  
Subject: RE: Study ref: 10/H0403/17  
Date: Tue, 11 May 2010 19:52:41 +0000

Trish

I wondered if you had received a reply from the chair yet? I'm working to a tight deadline and need to get data collected as soon as possible.

Many thanks,

Jenny Smith

---

Subject: RE: Study ref: 10/H0403/17  
Date: Wed, 28 Apr 2010 12:26:10 +0100  
From: Trish.Wheat@nottspct.nhs.uk  
To: jenny\_anne\_smith@hotmail.com  
CC: mgresswell@lincoln.ac.uk

Dear Jenny

I have forwarded your query to the Nottingham 1 REC Chair for her advice. I will contact you once I receive a reply.

Best Wishes

Trish

Ms Trish Wheat | Committee Coordinator

Nottingham Research Ethics Committee 1


Direct line 0115 8839390 | Switchboard 0115 8839530

1 Standard Court, Park Row, Nottingham, NG1 6GN

Email: [trish.wheat@nottspct.nhs.uk](mailto:trish.wheat@nottspct.nhs.uk) | [www.nres.npsa.nhs.uk](http://www.nres.npsa.nhs.uk)

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**From:** Jenny Smith [mailto:[jenny\\_anne\\_smith@hotmail.com](mailto:jenny_anne_smith@hotmail.com)]

**Sent:** 28 April 2010 12:13

**To:** Wheat Trish - Administrator - NCTPCT

**Cc:** mark gresswell

**Subject:** Study ref: 10/H0403/17

Trish

I have received a favourable ethical opinion for my study (ref: 10/H0403/17), but have now encountered a difficulty with accessing patient identifiable information, and need clarification from the committee about how to proceed.

I am based on the Trent Doctorate in Clinical Psychology, which is split between Nottingham University and Lincoln University. I am enrolled as a student at both Universities, and the course has offices and secure storage at both sites. My participants are sending their consent forms and contact details to the office at Lincoln University, but I live and work in Nottingham. The participants are from Notts Healthcare. I will find it impossible, due to work commitments, to get to Lincoln University to contact participants and request permission to have the details forwarded to, and securely stored at, Nottingham University instead. Nottingham University has the same facilities for data storage as Lincoln, and I am a registered student at Nottingham as well as Lincoln.

I am also planning to use a transcriber, which was not part of the original plan. Time restrictions means that it will no longer be possible for me to transcribe the interviews myself. The course has a confidentiality agreement for the transcriber to sign, and they will not be given names of participants, only numbers.

Do these constitute major amendments? I would appreciate confirmation of how to proceed and would be very grateful if this could be dealt with as soon as possible, due to my time constraints.

Thank you for your help,  
Regards



### 3. Confirmation of amendment

#### Nottingham Research Ethics Committee 1

1 Standard Court  
Park Row  
Nottingham  
NG1 6GN

Tel: 0115 8899393 (Direct Line)  
Fax: 0115 9123300

18 May 2010

Miss Jennifer Smith  
Trainee Clinical Psychologist  
Department of Learning Disabilities  
Highbury Hospital  
Highbury Road  
Bulwell  
Nottingham  
NG6 9DR

Dear Miss Smith

**Study title:** How do women under the care of eating disorder services experience sibling relationships: a phenomenological perspective  
**REC reference:** 10/H0403/17  
**Protocol number:** 4  
**Amendment number:** Amendment 1 - Minor  
**Amendment date:** 18 May 2010

Thank you for your letter of 18 May 2010, notifying the Committee of the above amendment.

The amendment has been considered by the Chair.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

#### Documents received

The documents received were as follows:

Document	Version	Date
Notification of a Minor Amendment (Emailed)	1	18 May 2010
- Change of address for return of Consent Forms & storage at Nottingham University		
- Using a transcriber		

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**10/H0403/17:**

**Please quote this number on all correspondence**

Yours sincerely

**Ms Trish Wheat**  
**Committee Co-ordinator**

E-mail: [trish.wheat@nottspct.nhs.uk](mailto:trish.wheat@nottspct.nhs.uk)


Copy to: Dr Mark Gresswell  
University of Lincoln  
Court 11, satellite building 8  
Brayford pool  
Lincoln, LN6 7TS

R&D Department for NHS care organisation at lead site -  
Nottinghamshire Healthcare NHS Trust

#### 4. Lincoln University ethical approval

Page 1 of 1

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 You forwarded this message on 25/03/2010 21:14.

---

**Jennifer A Smith (058044250)**

---

**From:** Emile van der Zee **Sent:** Wed 24/03/2010 23:55  
**To:** Jennifer A Smith (058044250)  
**Cc:**  
**Subject:** ethical approval  
**Attachments:**

Dear Jennifer, this is to confirm that you have ethical approval from today. Your application was very good, and carefully worded.

There was only one small thing that occurred to us when reading your documentation:

In your info sheet: "... you have one or two brothers or sisters" might rather be "... you have one or more brothers or sisters".

Good luck with your study, all my best,

Emile

Emile van der Zee: PhD  
Principal Lecturer in Psychology  
Programme Coordinator MSc in Child Studies  
School of Psychology  
Brayford Campus  
University of Lincoln  
Lincoln LN6 7TS  
[evanderzee@lincoln.ac.uk](mailto:evanderzee@lincoln.ac.uk)  
<http://www.lincoln.ac.uk/psychology/staff/683.asp>

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<https://email.lincoln.ac.uk/exchange/058044250/Inbox/ethical%20approval.EML?Cm> 30/11/2010

## 5. R&D approval

**positive**

Nottinghamshire Healthcare **NHS**  
NHS Trust

Positive about mental health and learning disability

**Research Management and Governance**  
Institute of Mental Health  
2<sup>nd</sup> Floor, Duncan MacMillan House  
Porchester Road  
Nottingham  
NG3 6AA

E-mail: Jayne.simpson@notlshc.nhs.uk  
Direct Line: ext 10661 / 01663

Our ref: AMH/22/05/10

Tel: 0115 968 1300

Date: 22<sup>nd</sup> June 2010

Dear Jennifer Smith

I am writing to confirm that the following study is authorised to take place within our Trust:

**Title:** How do women under the care of eating disorder services experience sibling relationships: a phenomenological perspective.

**Directorate(s):** Eating Disorder Services  
**Start Date:** 22/06/10 **End Date:** 31<sup>st</sup> October 2010

**Outline:** The study looks at the experiences of women who use the eating disorder services in Nottinghamshire in regards to their relationships with their siblings. Participants will be interviewed using semi structured interviews, 10 participants will be recruited, interviews will be transcribed and analysed using IPA techniques.

**LOA:** not required

We wish you well with your work. In accordance with the Research Governance framework, The Trust RMG Department follows up such work to assess its impact and influence on practice and policy. You will receive a brief progress report form to complete six months after the start of your study which will provide you with the opportunity to let us know of any problems you may be having. We will also ask you for some information at the end of your study.

The Resource, Duncan Macmillan House, Porchester Road, Nottingham NG3 6AA  
Chair: Professor Clair Chilvers, Chief Executive: Mike Cooke

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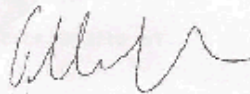
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NSJ NT  
100  
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Please keep this letter with you during the course of your research to confirm that you have Directorate and RMG Dept. approval, to gain access to the areas where your research is taking place. If you or others have concerns they can contact the RMG department on 0115 9691300 ext 10663 or mobile 07747 030196 or by email to [jayne.simpson@nottshc.nhs.uk](mailto:jayne.simpson@nottshc.nhs.uk).

Yours sincerely



Dr Peter Miller  
Medical Director

Cc: Mark Gresswell – Study Sponser

## Extended Paper

### Extended Introduction

#### Eating Disorders Literature

Eating disorders are categorised by the Diagnostic and Statistical Manual of Mental Disorders, Version Four – Text revision (DSM-IV-TR, American Psychiatric Association, 2000) into:

1. Anorexia Nervosa
2. Bulimia Nervosa
3. Eating Disorders not otherwise Specified

1. Anorexia Nervosa (AN)

Anorexia Nervosa (AN) is defined by an enduring restriction of calories, leading to a long term loss of body weight. AN is relatively common, the reported prevalence varies, but is around 0.3% (Hoek, 2006). Over the last 100 years, the incidence of AN has increased steadily, and the most substantial increase was among females aged 15-24 years (Hoek, 2006).

The incidence rate refers to the number of newly identified cases each year. Hoek, Bartelds, Bosveld, van der Graaf, Limpens, Maiwald & Spaaij (1995) found an average incidence of 8.1 per 100,000 during a study of general practice notes in the Netherlands between 1985 and 1989. This has been replicated in the UK (Lucas, Crowson, O'Fallon & Melton (1999).

The ratio of female to male cases has been reported at 11 to 1 (Hoek *et al.*, 1995), although there are very few studies which report incidence rates for men. There are methodological problems with all epidemiological studies in the eating disorder field. EDs are developed and maintained covertly, and individuals tend to try to avoid diagnosis and treatment (Hsu, 1996). Also, it is present in relatively low numbers in the general population, which means that high numbers of people must be studied to provide sufficient statistical power. This makes the studies expensive and time consuming. Many studies have attempted to address this difficulty by using case notes or hospital records to perform retrospective analysis of the data. However, this represents only the diagnosed and treated cases and cannot provide an accurate measure of the real number of ED cases in the general population (Hsu, 1996).

AN is accepted as a dangerous condition and studies have calculated the standardised mortality rate (SMR). This refers to the proportion of the people who die from AN compared to the expected mortality within age matched peers. Nielsen (2001) found that individuals with AN have a fourfold risk of dying compared to their healthy peers over a 20 – 40 year period.

## 2. Bulimia Nervosa (BN)

BN is characterised by calorie restriction and purging, or excessive eating and purging, with laxatives, vomiting or other means. BN is thought to be more prevalent than AN, though it is much more difficult to identify, since individuals experiencing this disorder often do not seek help and symptoms can be more difficult for others to identify (Collier & Treasure, 2004). An individual with BN

may not present as significantly underweight, so the disorder may not be identified.

Fairburn & Beglin (1990) have measured the prevalence of BN at 1%, which continues to be the accepted figure.

The incidence of BN has been difficult to assess, as the ICD-10 (WHO, 1992) was the first version to contain a definition of BN. Previous versions of the ICD had not referred to BN, though DSM-III (APA, 1980) contained diagnostic criteria for the condition. However, the three main studies to address this have reported an incidence rate of around 12 per 100,000. (Hoek *et al.*, 1995; Soundy, Lucas, Suman & Melton, 1995; Turnbull, Ward, Treasure, Jick & Derby, 1996).

The Soundy *et al* (1995) study also provided sex ratio information. They identified a ratio of 33 women for each man diagnosed with the condition and the Hoek *et al* (1995) study found a ratio of 27 women for each man diagnosed. However, these may be problematic figures. Women are more likely to attend their GP with symptoms and are more likely to admit to eating problems than men. It is possible, therefore, that there are more men experiencing eating difficulties than we are aware of.

Nielsen (2001) has calculated SMR of BN at 1.5%. This means that individuals with BN are also at greater risk of dying than their healthy peers. The study did not provide information as to the specific causes of death.



### 3. Eating Disorders Not Otherwise Specified (EDNOS)

This category is applied to individuals with significant eating problems who do not meet specific criteria for either AN or BN. No epidemiological information is available on this category, but Waller (2008) estimates that they account for at least 50% of clinical cases. However, it is relevant to consider here as some researchers believe that diagnostic crossover is common and individuals move between presentations at different time points (Eddy, Dorer, Franko, Tahlilani, Thompson-Brenner & Herzog, 2008). Some studies have shown that up to 50% of individuals with AN will go on to develop BN (Strober, Freeman & Morrell, 1997). This may have implications for EDNOS, since these individuals might previously have shown evidence of AN or BN, or may do so in the future.

#### Fairburn's Transdiagnostic Model

It is sometimes difficult to identify the particular disorder an individual is presenting. AN and BN are both characterised by restricted food intake and hypervigilance to body shape and weight. Over-exercising, vomiting and the misuse of laxatives are also present in both conditions. The main difference between the two subtypes is effect on body weight. Individuals with AN are likely to have a greater emphasis on restriction, and subsequently, a lower body weight, than individuals with BN, who alternate between bingeing and purging with a subsequent weight in the normal range (Fairburn, Cooper & Shafran, 2003). A longitudinal perspective on each individual often shows that the person originally diagnosed with AN may cross over into BN (Sullivan, Bulik, Fear & Pickering, 1998). Indeed, Agras, Walsh, Fairburn, Wilson & Kraemer

(2000) estimate that up to 25% of individuals diagnosed with BN have experienced AN in the past. EDNOS is a common diagnosis for individuals who have also been diagnosed with AN in the past (Sullivan *et al.*, 1998) and individuals diagnosed with BN often move to a diagnosis of EDNOS (Fairburn, Norman, Welch, O'Connor, Doll & Peveler, 1995). The development of different symptom presentations is not clearly understood, but it is hypothesised that age is a relevant factor. Individuals diagnosed in mid-adolescence typically present with restrictive AN while those diagnosed in late-adolescence typically present with BN (Fairburn, Cooper & Shafran, 2003). An ED which persists from mid to late adolescence is likely to develop from AN into BN (Fairburn *et al.*, 2003). This transition is so common that Eddy *et al.* (2002) have suggested that AN would be better viewed as a 'phase' in the course of the ED.

### Suggested Causes of Eating Disorders

#### Genetic Model

Strober, Lampert, Morrell, Burroughs & Jacobs (1990) has reported a tenfold risk of developing AN in women with female relatives who are also diagnosed with the disorder. The same study also showed that BN is clustered in families. However, this study was unable to account for this cluster effect and the role of shared family environments, stressors or other factors was not considered. Twin studies are often viewed as a useful way of identifying possible genetic factors. Some support has been shown for the genetic model through this approach. For example, Crisp, Hall & Holland (1985) showed a concordance rate of 55% for AN in monozygotic (identical) twins compared to 7% of dizygotic

(non-identical) twins. Treasure & Holland (1989) showed a concordance rate of 45% for monozygotic twins compared to 7% for dizygotic twins. This evidence appears to show support for the genetic model in AN, but the results with BN do not. Kendler, MacLean, Neale, Kessler, Heath & Eaves (1991) showed a 26% concordance rate for monozygotic twins compared to 16% for dizygotic twins, while Treasure & Holland (1989) showed a rate of 35% compared to 25%.

There are some serious problems with this model. Firstly, twin studies have been criticised for simplifying the relationship between genetics and the environment. Identical twins may be more likely to be treated in a very similar way than non-identical twins, which would confound the supposed genetic influence (Ogden, 2003). Finally, the prevalence of ED has been increasing, which the genetic model cannot account for.

### Psychoanalytic Model

Psychoanalytic models aim to provide an explanation for the particular individual's experience and, as such, they place an emphasis on the meaning associated with symptoms, as well as the early childhood experiences which are hypothesised to account for the disorder. For example, Dare & Crowther (1995) describe hunger as an "invincible, intrusive force" which needs to be resisted. The resistance leads to increased fear, which leads to increased weight loss. Earlier theories also emphasised aspects of sexuality. For example, Bruch (1965) who believed that the individual was "dieting away" the physical features of sexuality.

Early childhood experiences have been considered by psychoanalytic perspectives. Bruch (1985) suggested that a child who feels powerless within the family may use their food intake as a means to regain control over others. Goodsitt (1997) suggested that BN reflects an internal conflict regarding the relationship with the mother. The binge cycle reflects a desire to become close to the mother, while the purge cycle reflects a desire to reject her.

Psychoanalytic models, however, cannot account for the increase in prevalence or the reasons why food become relevant to the child. They do not explain why food is the chosen means of expressing distress. The models are also difficult to test or evaluate.

### Family Systems Model

This model states that it does not seek to attach blame to families, but to provide a context in which the ED is embedded. Eisler (1993) explains that the causality of EDs is circular, not linear, in that it develops within the context of a family relationship and also becomes a part of that relationship. The family systems model has four central components (Minuchin, Rosman & Baker, 1978; Palazzoli, 1974):

1. Symptoms as communication

The symptom replaces verbal communication when individuals feel unable to express their needs or emotions in more usual ways. They signify that something is wrong and that the individual wants to change things.

## 2. Homeostasis

Equilibrium is important within the family system and the ED is an attempt to maintain this. The main issue is, therefore, not the ED itself but the imbalance which the ED is attempting to correct.

## 3. Boundaries

Boundaries between members of the family are important, for privacy, development and personal space. These boundaries can be damaged and individuals can be enmeshed, over involved or distant. Strong associations can form between some members and exclude others.

## 4. Avoidance of conflict

Some families may avoid conflict and ED symptoms can develop as a distraction to unexpressed needs or emotions. Other families may be in perpetual conflict and the symptoms can develop as a unifying distraction.

Though the family systems model states it does not actively blame family members for the development of EDs, the 'fault' is implicit within the model. Family members learn that the way they function together has created the ED, which can be detrimental to all members of the family. The model also does not explain why an individual develops eating problems as opposed to other difficulties, such as depression, psychosis or self-harming behaviours. However, this model can explain why EDs are more prevalent in western

cultures, why psychological distress develops and why the majority of individuals with a diagnosis are female.

### Sociocultural Model

This model considers theories of gender, identity, social space, the meaning of food and the meaning of body size in its hypothesis of the development of EDs. This model states that it is not possible to understand the development of EDs without understanding the wider social context, beyond the family structure, in which it is embedded.

#### 1. Gender

Gordon (2000) suggests that EDs are a direct result of the conflict of gender, created by the demands placed on women in our modern society. This may explain why EDs appear to be increasing, but appears to neglect the fact that EDs also occur in men. Thornton, Leo & Alberg (1991) labelled this “superwoman syndrome”. They identified a conflict between conforming to traditional gender role identity, such as wife, mother, carer and domesticity and more modern goals of careers, independence and self-sufficiency. They found that symptoms of EDs were more common in women attempting to balance these aspects than in women who focussed specifically on one role.

#### 2. Identity

The concept of identity in this model is concerned with dichotomies, such as ‘dependence’ versus ‘independence’ or ‘adult’ versus ‘child’ roles. Gordon (2000) suggests that the radical changes in social expectations of women make

them more susceptible to identity confusion. However, this does not acknowledge the fact that male roles have become less clearly defined in line with female roles, yet males are considered to be less likely to experience EDs.

### 3. Space

Orbach (1993) suggests that EDs are a means of reducing one's body size in order to occupy less physical and social space. This can be seen as contrasting with the individual's desire to be noticed or attended to, or it can be viewed as matching the desire to disappear or go unnoticed.

### 4. Meaning of food

Food is hypothesised to play an important role in women's lives, through its expression of love, pleasure, caring and nurturing, as well as a source of conflict and power. This, particularly in western cultures where food is abundant, can be seen as a way of articulating a statement of the self which cannot be verbalised (Dana, 1987). Again, however, the meaning of food for men is overlooked in this idea.

### 5. Meaning of body size

Media representations of women emphasise the idea that thinness is equal to attractiveness and that thin women are in control, free and successful. Our society equates eating with lack of control, gluttony or weakness, and this is seen as undesirable. Body shape and size is, therefore, a powerful means of communicating a message to others. Gordon (2000) describes this as "the vocabulary of discomfort".

However, it should be noted that almost all western women are confronted with this image of feminine perfection within the media. All are exposed to the airbrushed, cleverly presented images of ideal women, which cannot be replicated in the real world. However, not all women develop EDs. The validity of the idea appears convincing in the proliferation of diets, exercise regimes and surgical procedures which are now on offer, the majority of which are targeted at female audiences, but this model cannot explain why we have not all succumbed to this pressure. It also has yet to fully consider the impact of media representations of ideal masculinity on men.

#### Cognitive Behavioural Model

These models of EDs use the central components of behaviourism, such as conditioning, reinforcement and extinction.

AN can be viewed as a learned behaviour which has been maintained through reinforcement: Being overweight, or not conforming to media images of ideal body shape, leads to a belief that one is unattractive. This leads to a process of weight loss which is reinforced through attention from others (Ayllon, Haughton, & Osmond, 1964) and a feeling of being in control (Wyrwicka, 1984).

Slade (1982) suggested antecedents to this process in dissatisfaction with the self and the family, and the internal attribution of failure. However, these models are predominantly behavioural in their focus and do not specify a role for cognitive processes, though these could be implied within the process of being dissatisfied with the self and beliefs about failure.



DeSilva (1995) suggested six cognitive dysfunctions which could be identified in AN, based on those originally proposed by Beck (1976). These are:

1. Selective abstraction – focussing on selected information, such as the appearance of individual body parts, or the calorie content of foods
2. Dichotomous reasoning – ‘all or nothing’ ideas, such as “if I eat one piece of chocolate, I might as well eat all of it”
3. Overgeneralisation – drawing global conclusions from single events. For example, generalising the weight gain obtained by eating high fat food, to that of eating a healthy, balanced diet
4. Magnification – exaggerating consequences, such as “if I eat anything at all I will become obese”
5. Superstitious thinking – connecting unconnected processes, for example, “I will put on weight if I touch that food”
6. Personalisation – self-centred event processing, such as assuming everyone is looking at your weight or body shape

Cognitive behavioural models have also been applied to BN. Fairburn (1997) demonstrated the importance of perfectionism and dichotomous thinking in maintaining BN. The model proposed that the person views themselves on the basis of body shape and weight, through a set of rigid rules about food, for example, “I must not eat any chocolate”. However, mood fluctuations can lead to a rule break, which leads to the dichotomous thinking of “I have failed so I may as well eat all of it”. The person then attempts to moderate the negative affect associated with the binge by purging themselves, typically through

vomiting or laxative use. The purge, in turn, reinforces the binge by removing the sense of guilt associated with the overeating.

The main problem with cognitive behavioural models is that they do not account for the reasons why only a relatively small minority of women develop EDs, when the majority experience cognitive dysfunctions to varying degrees.

### Caring for the person with an Eating Disorder

There is an increasing awareness of the burden of care for families of individuals with EDs (Schene, 1990). The ED can have a significant impact upon the whole spectrum of family life – socialising, routines, leisure, finances, working patterns, shopping habits and mealtimes are all disrupted, to the extent that the physical and psychological health of carers can be damaged (Perring, Twigg & Atking, 1990). Emotional reactions in carers include guilt, shame, anger, grief and disbelief (Perednia & Vandereycken, 1989) and inadequacy as a parent (Wood, Flower & Black, 1998). Treasure, Szmulker, Todd, Gavan & Joyce (2001) compared the experiences of carers of those with EDs with those of carers of people with psychosis. They found that carers of people with EDs reported more practical problems and higher levels of psychological distress. This is a significant study as it was the first time that the extent of the impact upon the family had been considered. They asked a group of carers of people with EDs (n=71) and a control group of carers of people with psychosis (n=68) to complete the General Health Questionnaire (GHQ) and the Experience of Caregiving Inventory (ECI). The group of carers contained parents, siblings, partners, friends, children and 'unspecified' relationships. The main difference

was that carers of people with EDs were predominantly parents (60%), while the carers of people with psychosis were more evenly distributed. Interestingly, 12% of the carers of those with EDs were siblings, while none of the carers of those with psychosis described themselves as such. Also, 76% of the people with EDs lived with the carer being assessed, while only 54% of those with psychosis did so. This study demonstrates the severity of difficulty experienced by carers, but does not consider how the person with the ED or psychosis experiences this relationship.

Difficulties with interpersonal relationships and, more specifically, family relationships (Enten & Golan, 2009; Klump, Wonderlich, Lehoux, Lilienfeld & Bulik, 2002; Ringer & McKinsey Crittenden, 2007; Strober & Humphrey, 1987; Whitney, Murray, Gavan, Todd, Whitaker & Treasure, 2005), have been consistently identified. Since many individuals with eating disorders are children and adolescents, the focus on family relationships is highly significant. Large numbers of these adolescents will continue to meet criteria for a diagnosis of eating disorders into adulthood. Due to the nature and severity of the emotional, developmental and cognitive problems these adults experience, many remain living in the family home until a much later stage than their peers (Ratnasuriya, Eisler, Szmulker & Russell, 1991).

Haigh & Treasure (2003) developed the Carers Needs Assessment Measure (CaNAM) to specifically identify the needs of all family members and carers of people with EDs. They invited 12 carers of people with AN to participate in a focus group and identified unmet needs in the areas of 'information about eating disorders', 'support from others' and 'information from GPs'. They used this

information to create the CaNAM and then carried out a test of this measure with 28 carers. This study provided clear information about the unmet need of a small group of carers, though it is unclear how representative of all carers this sample was.

Huke & Slade (2006) investigated the impact of EDs on partners. They interviewed eight partners of individuals with BN and, using IPA methodology, they identified five themes from the data. These were: living with secrecy and deception, struggling to understand, discovering powerlessness, learning to live with it and strengths and strains within the relationship. This study suggested it would also be useful to consider the relationship from the perspective of the individual with BN as a comparison, though it was not possible due to time constraints.

Parental experiences were investigated by Whitney, Murray, Gavan, Todd, Whitaker & Treasure (2005). They analysed narratives written by parents involved in family therapy at a specialist inpatient unit. They used 20 fathers and 20 mothers, of 27 inpatients and used grounded theory to analyse the content of the letters. They identified six higher-order categories: perceptions of the illness, treatment control, illness coherence, effect on family, emotional responses and cognitive strategies. Within these categories, they identified 'significant gender differences'. Using a computerised text analysis (Linguistic Inquiry and Word Count), which reads each word in the text and assigns each word to one of over 70 categories, they found that fathers were significantly more likely than mothers to use cognitive and avoidant coping strategies, while mothers were significantly more likely to demonstrate an 'intense emotional

response'. However, the parents used in this study were already involved in family therapy, which may have altered their perceptions of the problems, and the analysed narratives were produced as part of that therapy. It is possible that parents may have emphasised different aspects of their experience if they had been specifically asked to write for the research study.

Stein, Woolley, Cooper, Winterbottom, Fairburn & Cortina-Borja (2006) have considered the effects of EDs on children of mothers with a diagnosed ED. They assessed the children of 33 mothers with EDs and compared them to those of 23 mothers without EDs using interviews and observations of the mothers and children interacting. They found that the children of mothers with EDs scored significantly higher on three out of four domains of psychopathology assessed by the Eating Disorder Examination – Child version. They found that this increased eating disturbance was influenced by the length of time they had been exposed to their mother's disturbed eating. However, this study focussed specifically on the mother's eating problems and did not assess any eating difficulties experienced by the fathers, and the sample was relatively small for the statistical techniques employed. Further data is needed to increase the power of this result.

### The Sibling Literature

#### Sibling relationships

Bank & Kahn (1997) began researching the nature of sibling relationships in the early 1980s. They felt that psychodynamic theory had identified the concept of 'sibling rivalry' (Levy, 1937) and that this notion had become culturally

embedded and used to define sibling relationships in their entirety. They identified, for the first time, that siblings have a 'bond', which encompasses a multitude of experiences and emotions, which are not simply limited to rivalry. They distilled their research into the sibling bond into the following 'essence':

1. Siblings provide stability and familiarity in a changing world
2. Siblings are with us throughout the lifespan and remind us of our mortality
3. Siblings define our life journey, whether comfortable or uncomfortable
4. Siblings share secrets in a co-constructed core of memories
5. Siblings can provide care and support if a parent is unable to do so
6. For some siblings, the relationship is damaging or inconsequential

Gass, Jenkins & Dunn (2007) investigated the hypothesis that sibling relationships could be protective. They used a longitudinal design to investigate how the sibling relationship mediated adjustment to stressful life events. They found that sibling affection did influence the degree of internalised symptoms (such as depression), but did not have any effect on externalised symptoms (such as aggression). They also showed that this effect was present regardless of how positive or negative the mother-child relationship. This is interesting in that it demonstrates firstly that sibling relationships are indeed important to psychological wellbeing and, secondly, that these relationships can compensate for less supportive parental influences. However, their measurement of sibling relationship quality may be problematic. They asked the elder of the siblings to rate their views, but did not ask the 'target child', i.e. the child whose symptoms were being measured. This provides only one opinion of the dyad and may not

reflect how the younger sibling feels about the relationship. Despite this, it appears that this study found evidence of a protective effect of sibling relationships, if those relationships are experienced as positive.

Bank & Kahn (1997) proposed the idea that sibling relationships differ in nature according to demographic characteristics. For example, the relationship between a pair of siblings with a small age gap, with the subsequent shared experiences of same schools, friends, home and parenting style is likely to be qualitatively different to that of siblings born many years apart. These siblings may not share any experiences and may even seem to belong to different generations. They also discovered, following an eight year study of 100 sibling sets (1997), that strong sibling bonds develop when three conditions are met:

1. High access between siblings (i.e. close, frequent contact)
2. The need for meaningful personal identity
3. Insufficient parental influence

Cicirelli (1985) defined sibling relationships as:

“the total of the interactions (physical, verbal and nonverbal communication) of two or more individuals who share, knowledge, perceptions, attitudes, beliefs and feelings regarding each other, from the time that one sibling becomes aware of the other. A sibling relationship includes both overt actions and interactions between the sibling pair as well as the covert, subjective, cognitive and affective components of the relationship”.

This definition makes a useful distinction between the overt behaviours of the siblings and the covert behaviours. This is needed in order to consider the underlying emotions and experiences of the individuals involved, which may be in opposition to the behaviours they are obliged to present.

Cicirelli (1995) also outlined the unique characteristics of sibling relationships, as opposed to relationships with friends, parents and partners. He identified the following:

1. Duration – a sibling relationship is often the longest relationship a person has, longer than those with parents, friends and partners. This duration may add to the impact of this relationship on the person's life.
2. Ascription – a sibling relationship is not created voluntarily by the individuals involved, it is determined by the family of one's birth. This bond may allow for the relationship to survive more difficulties than relationships with friends or peers.
3. Intimacy – siblings usually live together within the same home and have close, daily contact with each other.
4. Equality – the author accepts that there may be some differences in power based on age, size, achievement and parental affection, but believes that most sibling relationships have a degree of equality which allows for communication and intimacy of a different type to the relationships with friends, colleagues and peers.
5. History – siblings usually have a shared history of events, memories and interactions, which is related to the duration of their relationship. This may impact the quality of the relationship.



This set of characteristics may be a helpful heuristic, in some situations, but it should be noted that not all sibling relationships are similar. For example, these appear to relate best to siblings raised within a single home, by both biological parents and with a small age gap. It would be questionable how many shared experiences, or how equal the relationship would be between siblings of a blended family, or siblings born many years apart. Even within families that conform to the typical pattern, it is not known how equal siblings really are, how similarly they may be treated by others, how they view each other or how long their relationship endures through adulthood in a meaningful way. More recently, Sroufe, Egeland, Carlson & Collins (2005) have adapted this set of characteristics. They are in agreement that these are likely to be the most enduring relationships that an individual experiences, but they explicitly state that they often involve “strong emotional ties”. Cicirelli (1995) did not refer to any emotional connection in his description. Moreover, Sroufe *et al* (2005) do not imply the direction of these emotional ties. Their view encompasses the possibility that these emotional connections may not always be loving and affectionate. They also state that these relationships may be a particularly useful means of learning how to manage emotional conflict, since our bonds with our siblings may be especially difficult to escape from.

#### Sibling relationships as part of the family system

Family systems theory postulates that all individual family members are “inextricably embedded” within the system and it is not possible to understand their experiences, beliefs, feelings and behaviours without the context of that system. McGuire & Shanahan (2010) take this another step further and explain

that families are embedded within cultural settings and any research attempting to address the relationships of family members needs to consider the cultural milieu. They point out that previous researchers, such as Cicirelli (1995), provided definitions of sibling relationships based on cultural norms for the United States and that these definitions may be less relevant cross-culturally. Their paper considered the experiences of European Americans, African Americans and Mexican Americans and found that they shared many sibling traits, such as the impact of parental behaviour on the sibling relationship, the effects of racial abuse and the influence of supportive, loving sibling relationships on health and psychological resilience. However, they also noted that there are many groups in which sibling relationships have never been studied, such as American Asian families, adoptive families, lesbian, gay, bisexual and transgender families and multiethnic families. They emphasise their view that there is no evidence for a “universal sibling process” and that these relationships need to be considered within their own family and cultural contexts.

### Factors Affecting the Sibling Relationship

#### Parental Differential Treatment

McHale, Updegraff, Jackson-Newsom, Tucker & Crouter (2000) and Richmond, Stocker & Rienks (2005) have investigated the role of parental differential treatment (PDT) on sibling relationships. McHale *et al* (2000) note that even very young children are able to identify when their sibling receives different treatment, and preschool age children begin to respond with phrases such as

“it’s not fair”. Some prior research (e.g. Kowal & Kramer, 1997) had noted an association between adolescents’ perceptions of their parents as fair and positive sibling relationships, leading to the hypothesis that it is not the act of treating children ‘the same’ but treating them ‘fairly’ that matters. McHale *et al* (2000) sought to investigate this further by interviewing the parents and first and second born siblings from 385 families. They found that ‘fair treatment’ was more closely related to positive sibling relationships than was ‘same treatment’, implying that the siblings were more able to respond positively to each other if they viewed their parents as responding to them fairly, but recognised that they have different needs and that parents may be unable to treat them the same. This appears to have some face validity, in that two siblings may be different ages and have, for example, a different curfew. It may be unfair to expect a 12 year old and a 17 year old to return home at the same time, while the parents may feel they are treating them ‘the same’, the siblings may view this as unfair. McHale *et al* (2000) also found that this sense of unfairness was linked to problems with the sibling relationship. Richmond *et al* (2005) assessed 133 families over three time points measuring behavioural problems, sibling reported relationship quality, PDT and depression. They found that sibling relationship quality improved over time and, as it did so, their depressive symptoms decreased, but their behavioural problems increased. They postulated that the reason for the changes were developmental in origin, in that the siblings developed emotional and cognitive skills between the ages of eight and 16 years (the studied time period) which enabled them to externalise any distress. It is possible that follow up when these children reached adulthood

might indicate that further development led to improvements in externalising behaviour. However, this is an untested hypothesis.

Sutor, Sechrist, Plikuhn, Pardo, Gilligan & Pillimer (2009) investigated this theory more recently. They asked 708 adults who were already part of a longitudinal family study, to provide information about their perceptions of maternal favouritism as children, and as adults. They found that those who perceived their mothers as favouring their siblings as children had more distant relationships with their siblings as adults. They also found that this effect was not mediated by their adult perceptions of favouritism. That is, even if they felt that they were currently favoured over the sibling who was favoured in childhood, the relationship with that sibling was not improved. This shows that parental favouritism, or the perception of this, can have lifelong effects on the sibling bond.

### Transitions to adulthood

Jewsbury Conger & Little (2010) examined studies of sibling relationships during the transition to adulthood. This is pertinent here, as it is often the adolescent period in which eating disorders begin or develop. It has been postulated that the transition to adulthood takes place between the ages of 18 and 25 years old (Arnett, 2004), and that it is during this period that responsibility and independence become significant concerns. However, Cote (2006) believes that the transition now lasts until approximately age 30, as individuals remain in education for longer periods and delay career choice or building families of their own until later. This may have a significant impact

upon sibling relationships, as siblings may remain in the family home for longer, may compete for financial resources from their parents and may spend greater periods of time together as adults than was previously the norm. Mouw (2005) showed that individuals followed the transition into adulthood using a framework of five key areas, which are leaving home, completing education, being employed, marriage and childbearing. However, these areas are specific to westernised cultures and this framework does not consider that many individuals will differ from this pattern. For example, people may remain in education throughout their lifetime, some may never gain employment, marriage or long term, committed relationships are no longer considered necessary for childbearing (Coontz, 2005), and many also choose either to delay childbearing until much later, as a result of advances in assistive reproductive technology or to avoid it entirely. Mouw (2005) noted within this paper that transitional stages into adulthood happened at different times, at different ages and under different family circumstances for each sibling. Thus, the transition into adulthood for an individual may be measured upon different criteria. However, while retaining these questions about the validity of this framework, it is possible to consider the sibling research undertaken in each area.

### Leaving home

Sibling relationships are likely to be significantly affected by one sibling leaving the family home. The nature of the impact this has will likely depend upon the quality of the relationship. For example, a relationship which is warm and affectionate may lead to a sense of loss as one sibling moves away, while one

that is hostile and competitive may result in a feeling of relief as the daily conflicts are removed (White, 2001).

White (2001) also found that the nature and frequency of contacts with siblings varied across the lifespan. In a study of more than 9,000 sibling sets aged between 18 and 83, White (2001) found that sibling social support declines in early adulthood, possibly in conjunction with one sibling leaving the home and having less frequent contact. This support was found to stabilise in middle adulthood and rise a little beyond the age of 70 years.

#### Completing education

Conley (2004) has pointed out that siblings within the same family may have different ideas about how far to pursue their educational goals, and that this is likely to be influenced by financial constraints, with larger families having reduced financial resources, academic capabilities and career interests. Sibling relationships could be damaged if some siblings are offered financial support to study while others are not, or if some siblings are provided with more support and encouragement. On the other hand, relationships could be strengthened with siblings who are able to offer support to each other or serve as positive role models.

#### Being employed

Obtaining a job or career has a significant impact upon the sibling relationship. Conley (2004) showed that siblings who share professional interests might

develop closer relationships, while relations are likely to suffer if siblings within the same family do not all find professional success or fulfilment.

### Marriage and childbearing

There is very little research to describe the nature of sibling relationships and the changes they experience resulting from one sibling getting married or cohabiting with someone (Prentice, 2008) but it could be suggested that these transitions will also impact the relationship. For example, a new member of the family is introduced when a sibling marries or moves in with somebody. This could add to existing tensions, could create new problems or may help siblings to develop more positive relationships. Similarly, the birth of a child is such a significant event in the life of the parent that it may exclude or lower the priority of any siblings. This could also add to tensions within the relationship. On the other hand, when siblings already have children, the new baby could be a source of common experience and shared interest.

Sibling transitions have been noted to occur at different times (Mouw, 2005). The age gap between siblings could be one reason why differences occur. For example, it may be reasonable to expect siblings who are two years apart to experience transitions at similar times, while siblings who are more than ten years apart would be less likely to do so. The number of siblings in the family may also be a relevant factor for determining transitions. Riggio (2006) found that individuals in their 20s with larger sibling sets reported more positive childhood memories than individuals with only one sibling. This could indicate that experiencing transitions at different times is a positive experience.

## Sibling conflict

Sibling conflict has been identified since the very first days of research into sibling relationships. The early psychodynamic literature identified the concept of 'sibling rivalry' (Levy, 1937), and this term has become part of the culturally accepted view of sibling relationships. While this referred to a need to compete for the attention and affection of a parent, it also encompasses feelings of jealousy, envy, anger and aggression. This can lead to conflict between siblings. Perlman & Ross (2005) demonstrated that 2-4 year old siblings can have an average of 7.65 disputes per hour, with approximately 11 interactions per dispute. This implies that siblings can spend much of their early years in conflict with one another. However, this does not provide any information as to the conflict of older children and adolescents. Siblings aged between 2 and 4 years are likely to spend much of their time together, as they are not yet at school. Older children, with the exception of twins, will spend more time engaged in separate activities, such as school, sports and playing with their own friends. This is likely to reduce the average number of conflicts per hour. However, there is no evidence that these conflicts will disappear entirely. It is possible that the nature, frequency and duration of conflict will change, but that it will continue to occur. Indeed, Kim, McHale, Osgood & Crouter (2006) followed 200 sets of sibling pairs from childhood to adolescence and rated the levels of sibling conflict at each point. They found that the level of conflict did not change throughout the assessment period, but that it began to reduce after early adolescence. This indicates that conflict does indeed continue beyond the early years.



### Sibling deidentification

The concept of siblings deliberately attempting to separate themselves from each other and form their own identity has been present in literature for decades (Schachter *et al.*, 1976). If one sibling is good at sport, the other may choose to focus on academic interests or deliberately refuse to participate in sporting activities. If parents, or the siblings themselves, are comparing themselves against the same goals and achievements, it would likely be felt as unpleasant to be the one who comes second. Schachter *et al.*, (1976) also suggested that the need to deidentify is linked to the perceived similarities within the relationship. For example, the efforts to deidentify are more marked with sibling pairs of the same gender, who are close in age than in sibling pairs of opposite sex or those with larger age gaps. These researchers also suggested that deidentification is a helpful process as it reduces rivalry and improves the quality of the relationship. However, this theory has not received sufficient research attention and Whiteman *et al* (2010) highlight the need to investigate the process by which deidentification occurs. Similarly to the need for further research into the optimum level of sibling conflict is the need to investigate the optimum level of deidentification. It is possible that identifying too closely with a sibling, across too many domains (e.g. sport, academic achievement, musical taste) may encourage rivalry and competition, while failing to identify with a sibling in any domain may encourage the relationship to dwindle entirely. It is also possible that the process of deidentification occurs predominantly in adolescence, when individuals are consciously involved in forming their identity (McHale *et al.*, 2001). This may mean that studies of this

period of development are likely to show more deidentification processes than studies of adulthood and beyond.

### The literature relating to individuals with ED and their siblings

Though the sibling relationships question has been largely overlooked (Blessing, 2007), some studies have considered this question. In 2006, Honey, Clarke, Halse, Kohn & Madden looked at the influence of siblings on the experience of Anorexia Nervosa (AN) for adolescent girls. This was a qualitative study using grounded theory methodology to investigate the experiences of women with an eating disorder through self report and parental report. They interviewed parents of girls with a diagnosed eating disorder and they also interviewed girls with a diagnosed eating disorder (not necessarily from the same families). They performed content analysis on the interview transcripts and used Grounded Theory to “identify and categorise the different ways in which participants discussed siblings”. The study found that sibling influence was perceived as highly significant in supporting recovery and it proposed a model of sibling interaction for clinical use. The study had a high number of participants and suggested useful clinical application of their findings. However, by considering the specific question of influence on the person with an eating disorder, they have not considered how the relationship between the siblings was experienced and important information may have been overlooked.

In Dimitropoulos, Klopfer, Lazar & Schacter's 2009 study, they asked 12 siblings of women with eating disorders to describe the impact on the family and identified six themes, however, these are not all themes according to traditional

grounded theory assumptions. For example “family factors”, “coping strategies” and “support systems” are likely to be clusters of themes requiring further analysis. The authors used these results to discuss implications for family therapy. This study provided very useful information about the nature of the relationships between those with an eating disorder and their siblings. However, it did not provide any information about the perception of the relationship from the perspective of the person with an eating disorder and it was not able to break the information down into specific themes. This may have been due to insufficient data or a paucity of theory to support the identification of specific themes. The use of Interpretative Phenomenological Analysis (IPA) here may have provided more information, at this stage of theoretical development.

Bachner-Melman (2005) has published a small study looking at this issue from the perspective of the person with an eating disorder. She asked four women with a diagnosed eating disorder to describe their relationships with their siblings. She then “ascribed categories of content” to sections of the transcribed interviews. It is not clear what method was used to do this. They each described relationships characterised by rivalry, antagonism and little warmth. This raises many interesting questions, such as whether the relationship had always been perceived that way, whether the perception had changed along with the development of the illness and how great an influence the sibling antagonism had on the course of the eating disorder. It also raises the issue of how well those with eating disorders accept the support offered from family therapy. However, this study was small, looking at the experiences

of four women. Those four women were disparate in terms of their ages, position in the family, number of siblings, degree of illness and stage of recovery. The method of analysis used is unclear and insufficient detail is provided to identify this. It is also unclear if any attempts were made to identify themes within- and across- participants. IPA methodology may have provided a more structured, replicable approach. Bachner-Melman suggested the study could be used as a pilot and a starting point to further address this question.

### Extended Method

#### Research Design

This study uses a qualitative approach to investigate the participants' experiences. The method of analysis chosen was Interpretative Phenomenological Analysis (IPA), which was chosen for a number of reasons:

1. The research question is embedded in an experiential philosophy
2. The literature in the area of sibling relationships is currently sparse and this study was designed to be exploratory
3. The question under investigation was specifically interested in the experiences and interpretations of the participants.
4. The few previous studies have utilised unstructured, informal analytical approaches (Bachner-Melman, 2005) or have not focussed on the lived experiences of the person with the eating disorder.

#### Participants

Smith, Flowers & Larkin (2009) provide guidelines on the number of participants required for Interpretative Phenomenological Analysis (IPA). They state that:

“the primary concern of IPA is with a detailed account of individual experience. The issue is quality, not quantity, and given the complexity of most human phenomena, IPA studies usually benefit from a concentrated focus on a small number of cases”.

Smith *et al* (2009), also indicate that inexperienced IPA researchers are likely to encounter methodological problems with large samples, and may be overwhelmed by the data. The figures they provide as a guideline for research as part of professional doctorates are “between four and ten interviews”.

In line with these guidelines, it was aimed to recruit five participants, to each be interviewed once. However, due to time constraints, three were recruited. Smith *et al* (2009) state that three participants is a useful number, as it allows for a detailed analysis of each case, but also provides an opportunity for analysis of similarities and differences across cases.

### Recruitment

The project was undertaken within two eating disorder services in Nottinghamshire. One service is located within the Nottinghamshire Healthcare NHS Trust and the other is an independent service. Meetings took place between the researcher and clinicians from both services to agree participation in the study and to consult on the design, the development of the research question and the interview schedule. A presentation was also undertaken by the researcher at the larger service to outline the purpose of the study, the role of clinicians and the planned timescale. The information contained within this presentation was also made available to clinicians from the independent

service. Clinicians were also invited to attend a feedback presentation at the conclusion of the study.

The inclusion criteria were as follows:

1. Female – chosen as the majority of individuals diagnosed with eating disorders are female
2. Aged between 18 and 30 – chosen to reduce the likelihood of participants struggling to recall childhood experiences
3. With one or two siblings – chosen in order to ensure participants did not have large variations in the number of siblings.

Siblings are defined as any full biological sibling, half sibling or step sibling that the participant has lived with at some time during their life.

The exclusion criteria were as follows:

1. Unable to provide informed consent – very low body weight can impair cognitive skills, or lead to perceptual disturbances.

Clinicians agreed to make the first contact with potential participants. They were given an information pack for themselves, which contained the following:

1. Information sheet (see appendix E1)
2. Inclusion / exclusion criteria (see appendix E3)
3. Statement of introduction to participants (see appendix E4)
  - a. This outlined the agreed method of introducing the study to potential participants, and was included following consultation with the clinicians.

Information packs for participants were also left at each service. These contained the following:

1. Information Sheet (see appendix E1)
2. Consent Form (see appendix E2)
3. Contact details form (see appendix E5)
4. Prepaid envelope

Clinicians agreed to consider whether they had any clients on their caseload who met the criteria, who might be interested in participating. If so, they agreed to introduce the study and hand the information packs to participants on behalf of the researcher. The participant information sheet contained contact details for the researcher, to enable questions or discussion before signing the consent form. Clinicians were also able to answer simple questions at the time of introducing the participants to the study.

Once signed consent had been received, the researcher made contact with the participant to arrange the interview. All interviews took place at the participants' usual therapy venue, though all had the option of choosing alternative venues if they wished. All participants were reminded that their participation was voluntary.

#### Information recorded about participants

The information recorded about participants was kept securely, in accordance with University policy and ethical procedures. Identifying characteristics of any participant were kept securely at the University, separately from interview transcripts, which only contained participant numbers. The demographic

information stored for each participant included name, age, number of siblings, residential status and ethnicity. These questions were chosen in order to monitor homogeneity of the sample, and to provide information about the nature of demographic differences between participants.

### Ethical Process

In April 2010, the researcher contacted the ethics committee to request approval for a minor amendment. This amendment was to enable the storage of participant contact details at Nottingham University, rather than Lincoln University. In May 2010, the committee approved the amendment. Research Management and Governance approval was granted by Nottinghamshire Healthcare NHS Trust in June 2010.

The main ethical consideration was that the participants may experience distress when discussing their sibling relationships. It was considered possible that the participants may consider their sibling relationships from a different perspective following the increased focus during the interview. All participants were asked to consider discussing the interview material with their treating clinician following the interview. Verbal feedback regarding the interview was provided to treating clinicians as soon after the end of the interview as possible. This was to ensure that clinicians were aware that their client had been interviewed and to pass on any concerns about distress levels or content. While all participants experienced some emotional distress during the interview, this appeared to be mild and short-lived. All participants reported feeling calm prior to leaving the interview.



### Semi Structured Interview

The interview schedule is attached in Appendix E6. It was designed by the researcher to provide a structure to the interview while maintaining the flexibility necessary for qualitative research. The questions were planned to be open and non-directive, in accordance with IPA principles (Smith *et al.*, 2009). The first part of the schedule addresses demographic and practical information, such as age, number of siblings and whether they currently live together. This was placed at the beginning in order to assist the participant to feel comfortable talking to the researcher, before moving onto more personal topics. The second part of the interview schedule asks broad, open ended questions about the sibling relationship, both historically and currently. These questions are focussed on the experience of sibling relationships, but are open to different aspects of that relationship. As with other IPA interview schedules, this is necessarily brief and open ended. Important information gathered in IPA interviews often arises from following up on initial answers with appropriate prompts, such as “can you tell me more about that?” Specific prompts were also included, such as “how did that feel?”, but most prompts were expected to occur spontaneously, in response to answers given by participants.

There were three interviews, which were all audio recorded, using an Olympus DSS digital recorder, and transcribed. The transcription was undertaken by an independent, professional transcriber, sourced from a list, held by the course, of previously used transcribers. The audio recording did not contain the participant’s name and the transcriber had signed a confidentiality agreement (see Appendix E7). Each interview was scheduled to last approximately one

hour, though this was flexible to allow for participants to discuss as much or as little as they chose. The actual interviews adhered closely to this plan, with a mean duration of 60.3 minutes (ranging from 56 to 63 minutes).

### Analytic Process

The analytical process followed the guidelines detailed in 'Interpretative Phenomenological Analysis: Theory, Method and Research', by Smith, Flowers & Larkin (2009). The process of IPA analysis can take different forms, but Smith *et al* (2009) recommend that first time researchers follow the stepped process as follows:

1. A line by line analysis of the text

This was achieved through reading and re-reading the transcripts. This allowed for familiarisation with the material and for initial thoughts to be noted. The researcher made initial comments on conceptual, linguistic and descriptive content, in order to facilitate a fuller understanding of the narrative. During this process, the researcher also recorded the most immediate observations in the reflective diary, in order to "bracket them off", as recommended by Smith *et al* (2009). This refers to the process of identifying assumptions and emotional reactions and making efforts to separate them from the analysis of the text, by recording them in a reflective journal and referring to this throughout the analysis. Themes and notes can then be compared to recorded assumptions and checked to ensure they have indeed arisen from the data. For example, in interview three, there was a strong sense of vulnerability in the body language and expressions of the participant. There is a likelihood of

reactions such as these colouring the analysis, so it is necessary to try to detach these from the process, by recording them elsewhere (see Appendix E8 for an example of an excerpt of a transcript, with notation).

## 2. Identification of emerging patterns

The next stage of IPA analysis is to use the initial notes to begin to form themes, as they emerge. Following the re-reading of the transcripts, there was a larger data set, consisting of the participants' interpretations and the researcher's thoughts about these. The themes identified were closely tied to the original text, but reflected in a concise statement. These statements were then listed in a word document, in the order in which they appeared in the text. The statements were then moved around, to form clusters, according to similarity.

## 3. The interpretation of meaning

The meaning of the statements was interpreted throughout the process of identification. When the list of themes was created and manipulated to form clusters, the meaning was interpreted further by the researcher. This informed the process of clustering. Each cluster was considered complete when it reflected a particular meaning, distinct from other clusters.

## 4. The development of a structure to illustrate relationships between themes

Relationships between themes were analysed using a method from Smith *et al* (2009). They suggest that themes can be typed onto separate pieces of paper and laid out on the floor. This allows similar themes to be placed together. The decision regarding which themes to place together was based on abstraction – grouping similar themes together and renaming them, subsumption – one theme bringing together a set of related themes, polarisation- linking themes which reflect contradictory ideas and numeration – noting the frequency with which a theme is mentioned (see Appendix E9 for an example of the superordinate themes). This process was then used to identify superordinate themes across participants.

5. The organisation of data allowing analysed data to be traced throughout the process

Records have been maintained of the process of analysis, from original transcript to initial identification of themes, through to development of superordinate themes.

6. Use of supervision to test and develop the plausibility of the interpretation

Supervision with both clinical and academic supervisors was utilised to check the plausibility of the identified themes. The supervisors selected an interview transcript and identified themes from their own perspectives. These were then compared with those of the researcher. Any disagreement was resolved through the process of discussion, renaming

themes, or some rearranging. This is addressed more fully in the 'validation and triangulation' section.

#### 7. Development of a full narrative

This occurred following the identification of themes. The process of analysis was recorded throughout in the reflective journal (see Appendix E10 for an excerpt, following an interview). The information from the journal, alongside the themes and superordinate themes was used to construct a full narrative of the participant's experience with her siblings (s). This narrative considers the experiences as individual components, or themes, but maintains the context of the participant's overall experience. Finally, a table was constructed which contains the final themes developed, and this formed the basis of the results section. Throughout this process, it was possible to trace the journey of the analysis, through the notation, development of themes and cross-comparison of themes, as all themes continued to be grounded in the verbatim text of the original interview transcript. All examples presented in appendices E8 and E9 refer to the development of one theme, for one participant. The italicised text demonstrates the links between each stage of the process.

#### 8. Reflection on one's own processes

Throughout this procedure, it was necessary to remain aware of, and try to separate from, my own initial thoughts and assumptions about the research question and the data presented. Smith *et al* (2009) suggest

that this process is best achieved through the maintenance of a reflective research diary or journal. This is a useful place to make notes of initial impressions from interviews and reactions to the participants' experiences, since these could influence the analysis. For a detailed discussion of the processes which informed my own responses to the transcripts, see the extended discussion. For an explanation of the theoretical position of the researcher, please see section entitled 'Position of Researcher'.

#### Process of validation & data triangulation

The concept of validity remains relevant in qualitative research, despite the key differences between quantitative and qualitative epistemologies (Smith *et al*, 2009). Since the process of IPA is interpretative by nature, it is vital that there is a mechanism to monitor the validity of the interpretations. Smith (1996) suggested that one method for ensuring validity is to assess whether all themes identified are plausible when compared against the data collected, and internally consistent with the overarching theme of the interview. He also suggested that raw data should be presented in the results section, to allow for readers to identify the source of the theme. This study has sought to achieve this through presenting verbatim quotes from the transcript alongside identified themes. He also states that it is useful to have the data reviewed by an independent person, or the participant. This study has sought to achieve this through consultation with supervisors regarding the plausibility of themes

identified. It is not possible to identify an objective 'truth' from the data, but it is possible to ensure the themes identified reflect the actual interview.

Finally, adherence to the IPA protocol as described by Smith *et al* (2009) has ensured that this study could be replicated by another.

### Position of Researcher

Within IPA, it is necessary to disclose the researchers' own perspectives and values, since the methodology requires interpreting the experience of the participants. When participants describe their experiences, they are also describing their own meaning making of the experience. This is known as a hermeneutic. The researcher then interprets this experience, which leads to a double hermeneutic. This process of interpretation is influenced by the researcher's values and epistemological stance.

I am a trainee clinical psychologist, with some very limited experience of working with eating difficulties. These difficulties have been present in individuals with other clinical problems and did not meet criteria for eating disorders, as defined by the DSM-IV-TR (APA, 1994). However, these difficulties did cause very low body weight, which was visible and which I found distressing to see. This meant I was concerned about my reactions to the participants, who also presented with very low body weight. I discussed this in detail with my supervisor and recorded these concerns in the reflective research journal. In addition to the anticipated distress regarding the visibility of the participants' low body weight, I also anticipated that axiological assumptions regarding eating and nutrition would be implicated. For example, my

relationship with food has always been based on enjoyment and health, so the cognitions associated with eating disorders are particularly incongruent to my values. This has also been recorded in my reflective journal and discussed in supervision. Following each interview, this incongruence was considered and reflected in the journal. Learning points were considered prior to the next interview. Other assumptions I made prior to the research were based on the likely nature of relationships between siblings. Previous research, though limited, has identified relationships characterised by competitiveness and hostility, and this finding affected my expectations of the results. However, I have never worked closely with individuals with eating disorders and have no clinical experience which would inform the nature of sibling relationships within this clinical population. This lack of experience was hypothesised to be useful, in that I did not have significant, pre-formed ideas.

It is also important to consider the researcher's epistemological stance in qualitative research. Epistemology is the branch of philosophy which deals with the notion of what knowledge is, and how it is gained. It is important in qualitative research because it affects how the data is interpreted. My own epistemological stance is consistent with a social constructionist perspective. This postulates that all knowledge and experience is culturally embedded within the individual's history, language and social world. As a result, all knowledge is a product of interpretation, which has been filtered through the culture and social world of the individual. However, as Willig (2008) highlights, the experience may be an interpretation, but it remains real to the individual.



## Extended Results

The three participants who were interviewed were quite different from one another, but shared a number of similar experiences. However, I will provide a brief précis of each participant before I continue to the results. IPA is concerned with the lived experience and these experiences are formed within the context of our histories (Heidegger, 1962). Names have been changed.

Amy. She is 24 years old and lives alone, following her discharge from hospital. She has one sister, older by eighteen months, who lives in a different city.

Jo. She is 21 years old and lives with her parents, following completion of a university degree, during which she lived away. She has one younger sister, aged 18. Her younger sister lives locally and visits regularly.

Sarah. She is 30 years old and lives with her parents, following a relationship breakdown. She has one older sister, aged 33 and one younger sister, aged 26. Neither of her sisters live in the family home. She also has a step-brother, but she has no contact with him, and has never lived with him.

### **Amy**

#### **'Seeking Balance'**

This theme was borne out of Amy's explanation of her need to differentiate herself from her sister, and reduce the risk of comparisons being made between them. She felt that she was the "academic" sibling, as a child, but that her sister had gone on to become the successful sibling, with a career, a Master's degree

and a long term relationship. Amy felt she and her sister had always made “deliberate” attempts to be different from one another, in order to ensure that the balance remained. For example, here she is describing their process of differentiation:

*“We’ve always compared each other, and.. you know, I used to get really angry if she bought any clothing that was similar to mine because we had quite distinctive styles.....I don’t know if it’s jealousy, like kind of a possessiveness about what we look like and who we are and who we’re friends with, and couldn’t really be friends with the same friends. It was just kind of like, I think there’s a lot of strange feelings of possession around things. She was good at netball, so if I was good at netball that would be an enormous threat, so I’d have to choose something different.....I wonder how much we tried to make ourselves have completely different corners”.*

When asked why she and her sister might have developed this approach, she replied:

*“Because it’s very hard work being in competition all the time, isn’t it?”*

Here, she is describing how their need to avoid comparison and competition has led them to make deliberate attempts to be as different as possible. Amy then goes on to illustrate her thoughts by using the example of the Williams sisters, from professional tennis:

*“If one of those played football and one played tennis then they could both be very, very good and you might compare them, but you’d be comparing them on their different fields”*

This difference in profession would prevent one of the sisters from being seen as better than the other. This example neatly explained her need to be as different from her sister as possible.

Amy describes her eating problems as both the cause of her perceived problems with her sister, and a protective strategy to ensure she is not compared with her. It also creates the 'balance' between them:

*"When I was very ill, it (the eating disorder) required a lot of attention..it was quite an important thing and so, I suppose, I had a sense of having quite a lot, in time and attention...and she had to be the stronger one.....without an eating disorder in the picture, you're kind of compared a bit, on a level".*

There were other ways in which Amy sought to create balance with her sister. She viewed her sister as "good" and "innocent", and when Amy felt depressed as a teenager, she sought to channel her "not so great energy" through staying out late and drinking alcohol, which her parents disapproved of.:

*"So if I'm going out drinking and things and she's still relatively innocent, then once again, it's about the balance coming in".*

### 'Being Bad'

For Amy, the experience of 'being bad' was two-fold. She felt that her sister blamed her, for the distress their parents experienced, and she had a very strong sense that this distress was indeed her fault. Her interpretation of her sister's blame was that she had tried being supportive and understanding over the years, but had reached a conclusion that there was no other option left but to blame her:

*"You know, there were periods maybe when I was about 15 when she was very supportive about things, and would spend a lot of time listening to me, erm, and trying to almost mediate the gap between me and my parents. But then I suppose it shifted into her being more protective of them"*

Her self-blame was very strong, however, and permeated the text throughout her words and tone of voice. For example, she believes that her relationship with her sister has been damaged by her eating disorder, and that it cannot be repaired until or unless she is able to behave differently:

*"I think my eating disorder and my attitude to food, when it's as near to normal as can be, then I think only then would we be able to start getting back to a place where we didn't have all that in the way"*

This places the emphasis on her own behaviour as the cause of the relationship problems with her sister. She also feels that her parents have been damaged over the years by her eating disorder, and that they have been worried and upset about it. The concern from her sister is based around the significant impact her behaviour has had on her parents. Since moving out, however, both Amy and her sister agree that removing her from the daily lives of their parents has improved the situation:

*"you know, they've turned into one of those really nice couples. And that's because I'm not there, so that's a good thing"*

While stating that this was a good thing, there was a real sadness in her voice which might suggest that she genuinely accepted the view that she had

damaged her parents, and was resigned to being separated from them, to protect them from her influence.

Amy never explicitly stated that she was 'bad' but she made many references to her behaviour and her presence causing tension, distress and anxiety to her family. When describing her sister as the "good" sister, she was implicitly labelling herself the "bad" sister.

When she was explaining her current relationship with her sister, now that they live in different cities and have little direct contact, Amy feels that they do "get on", but she added:

*"It's just kind of sad that all of this has got in the way and that, therefore, I'm to blame for it"*

She also has a very strong sense of how her influence is felt among her family:

*"When we're all together, that sense of wariness is still there. You know, assessing the impact that I'm having on mum and dad. We went out to eat last week, and I could just feel it, you know. Sitting around a table at a restaurant and she's just, it's like she's holding her breath for... how it's going to go, and what my parents are going to be feeling, and if they're going to be having a nice time".*

There have also been occasions during their relationship when Amy's sister has commented on Amy's appearance and her problems with eating:

*"She told me I looked awful, and she told me I was rather disgusting and selfish, and why didn't I think about the parents.....she doesn't always word things very well, but at least she's honest".*

Amy's apparent acceptance of these comments, and her perception of them as "honest", might indicate that she agrees with the description of herself as "disgusting and selfish".

### 'I Don't Correlate'

Amy felt strongly that she did not "correlate" with the world and that she was, in many ways, separate from others. She described how this had begun at school:

*"I didn't have particularly great friends at school. And I wasn't particularly sociable....I think it was at that point that I started going slightly underground in terms of things"*

She also stated that her relationship with her sister was affected by this sense that she was 'different' to other people:

*"Maybe some point about 13, I'd left kind of human reality...and after that I was in these unfamiliar places of using food and drinking...I just wish that I knew how to explain it to her I suppose"*

There was a subtheme identified within this theme, of 'Being Cut Off'. This was, in many ways, similar to the overall theme of not 'correlating' with others, but was different in that it reflected her physical separateness and her deliberate attempts to separate herself.

Amy describes how she avoids discussing her feelings or her eating problems with her sister now, as a way of keeping herself 'cut off':

*"When she says 'how are you?' and I say 'I'm fine'.....if I said 'well no, actually, things aren't that great', she'd be kind of like 'oh why?' There'd be this moment of anxiety, and it would just be the thought of trying to explain so much stuff, and how things feel and what it's like.....they're cans of worms. So I say 'no, no, things are good'"*

Amy also describes how this feeling of cutting herself off from others has made it harder to recover from her eating problems:

*"It's a very headstrong, I'm going to do this my own way. And I wish I was more receptive to someone just telling me, you know, eat that"*

Equally, she feels that her family have separated from her, which has also proved difficult:

*"You have to make your own decisions. We can't make any of them for you. Don't get us involved in a decision because...it emotionally ties us. Which is really infuriating because, you know, normally, I don't know which sandwich to have.. No Amy that's your decision. Don't implicate me in this. It's over everything".*

This feeling of separateness has been present since Amy's teenage years, as she describes how her sister would help to explain Amy to their parents, but would still be unable to help them understand:

*"You know there were periods maybe when I was about 15 when she would spend a lot of time listening to me and trying to mediate the gap between me and my parents.....I don't think she's ever fully understood any of it".*

## **Jo**

### **'Not Being Noticed'**

For Jo, the experience of being in her family, with her sister, is that her needs have been overlooked, in order to meet the competing needs of her sister. She stated:

*"She's been renowned for sort of having temper tantrums and, sort of, she always got her own way"*

This contrasts with the way she recalls her own behaviour:

*"My gramps was saying she's always been the one to kick off....I was always told that I was quite quiet. And I'd just sit there and happily play with my toys".*

Jo believes that their relationship was always volatile:

*"We never got on. We always, sort of, fought"*

This fighting increased in severity after Jo had left for University, as her visits home would often result in conflict between the sisters:

*"She didn't like the fact that I'd got home, and things started to get worse and she started to cause a lot of trouble between me and my parents"*



The fighting would lead to their parents intervening, and Jo recalls the feeling of being blamed:

*"We'd always be arguing and it would always be me that was to blame and it was always, sort of, said that it was fine in the week when I wasn't here".*

*"No matter whose fault it is, it's always me that's told to be quiet and always me that's blamed....it was always me that shouldn't have took the bait".*

When Jo's sister became involved in a relationship that their parents did not approve of, Jo felt increasingly ignored:

*"It was always her. You know, I'd be sat talking to them and she'd come in and she'd kick up a fuss and she'd shout and no matter what I was saying, I'd just get ignored. And even when I was there, they were sort of worrying where she was.....It just seemed that no matter what I did....I couldn't get any sort of recognition, cos they were just so focussed on her".*

Jo recalls a period of time as a child, spent in hospital having various operations. She does recall that her parents would visit her, but feels that she continued to be overlooked at weekends, when their parents would spend time with her sister:

*"I was still stuck in hospital and they were...everyone was, sort of doing things with her, sort of to treat her....because she was missing out, if you like.....it was me who was stuck in hospital"*

Once Jo had received a diagnosis of an eating disorder, she continued to feel overlooked, as her sister was diagnosed with Irritable Bowel Syndrome (IBS) at a similar time:

*“Very much another reason, sort of, at mealtimes, to please her and keep her quite happy....”Poor (sister), she can’t do this, she can’t do that”. Whereas no one ever mentions that I had anorexia. Ever”*

The subtheme of ‘Being Pushed Out’ was also identified and linked to this theme. It has much in common with the theme of ‘Never Being Noticed’, but differs in that it centres around examples of Jo feeling like she has been deliberately excluded, as opposed to unnoticed:

*“We all have our own little seats at home, you know, where you, sort of, you sit in the living room at night and I got in the other night, and she was sat in my seat, and there wasn’t a spare seat, so I ended up going upstairs....I said to mum, “I’m coming in a minute to have my tea” and mum said “well, (sister)’s in your seat, so you’re going to have to wait”*

Jo also felt that her only option for dealing with the conflict with her sister was to leave the room, but this created the dilemma that she would then be excluding herself from the family:

*“I just used to sort of storm off, if you like and just go and be on my own, because you couldn’t do anything, and then she’d be the one left downstairs”.*

*“I think quite often, I’ll walk away. But then again, I’ll be walking away and being on my own”.*

Some of the conflict between the sisters has been experienced by Jo as aggressive attempts to exclude Jo from the family:

*“She went absolutely mental, and she, you know, she started screaming and shouting and throwing stuff....she was screaming at me to get out and throwing stuff at me and saying “what are you doing here? We had the house, you’ve got to go. Get out of the house now””*

### ‘Mealtimes Are Stressful’

Jo describes her relationship with her sister as being punctuated with regular conflict, and much of that conflict has occurred around mealtimes. While her sister was small, she was a “picky eater” and the family focussed their efforts on encouraging her to eat and then, later, when Sarah was at University during the week, the conflicts would occur when she returned home at weekends:

*“It always just seemed that I’d get in around teatime and she’d sort of come in and start trying to show my mum and dad something”.*

Jo also felt that her sister dominated the family mealtimes, with her “pickiness” around food:

*“So it’s always been about sort of pleasing her, and mealtimes have always been quite stressful, quite tense....never enjoyable”*

*“We were having to fuss around the food to make sure it was what (sister) liked. Nevermind if it was what other people liked, it had to be what she liked ‘cos you know, she was picky. She didn’t like this and she didn’t like that and mealtimes were always stressful and it was always about keeping (sister)*

*happy. And when I came back from university, it always just seemed to be I'd got in on teatime and she'd always find a reason to sort of kick off".*

The drive to compete for attention seemed to be heightened at these family mealtimes, with both sisters appearing to be worried about being overlooked:

*"I mean, I didn't expect to be the centre of attention, you know. It just, sort of, would have been nice, to sort of, you know, have been said hello to. But then (sister) would always turn round and say "Oh you timed it so you'd just come in on teatime. Why do you always have to come and interrupt when we're having our meal? You've been away all week and then you just come in and expect us to drop everything""*

There are also occasions when Jo gets upset that her sister returns from her boyfriend's house and arrives at mealtime:

\_\_\_\_\_ *"When she got in the other night, she came right on teatime, with her boyfriend and we were just dishing out tea...and tea sort of got left because there was all the big fuss about her coming home"*

While talking through these experiences, Jo became upset :

*"I'm getting upset talking about it now....we'd have to wait for her to get in for teatime and if tea wasn't on the table, she'd kick off because she'd been at work all day...and if we'd started before she got in, she'd moan that we'd started.....everything did seem to coincide around mealtimes and it's just been a lot of conflict".*

These extracts seem to suggest that mealtimes were a source of sensitivity and distress for both sisters.

Linked to this theme, was the subtheme of 'Shying Away'. This was related to the intensity of the conflict at mealtimes and Jo's need to avoid this conflict. Jo describes how she chose to manage this conflict by walking away or leaving the situation, which often meant leaving her meal as well:

*"Well, I just got pissed off and went back out and then didn't end up having anything (food) until much later"*

Jo feels that, over time, this need to avoid conflict contributed to her desire to avoid family meals:

*"And it just got to the point where I didn't have meals with them...I've not eaten a meal with them unless we've gone out for a meal...I've always just had something different on my own, away from them, just because I can't bear it....I just took myself away from the situation"*

*"Like last year, it got to the point where I didn't have meals with them, just to avoid it".*

Specifically, Jo feels the need to avoid eating near her sister:

*"I just don't eat in front of her..I don't like her seeing what I'm eating or knowing what I'm eating.....or anything"*

Jo also describes how she feels this has contributed to her current pattern of starving during the day and bingeing at night, as it is safer to eat "when everyone is in bed".

### 'Everyone Runs Around After Her'

This relates to the strong sense of jealousy and resentment which appeared to affect Jo when describing her sister and the treatment her sister has received from their family. Jo appears unhappy that their parents, particularly their mother, spend considerable time focussing on her sister's needs, despite the fact that she feels that her sister does not treat their parents well:

*"She's said some things to my dad that's upset him...I've always been very, very protective of him...and she's said quite mean things to him....she never lets my mum give her a kiss or give her a hug. She always comes out with something quite rude"*

The tone of her voice seemed resentful while describing her sister's perceived lack of respect for their parents:

*"And she's bringing all her washing and just dumping it on my mum and dad"*

And there was a similar tone of possible resentment or hostility during this section:

*"I'd always eat whatever was put in front of me...it was all centred around her and what she was eating and what she was doing"*

Jo did feel that she was rewarded by her parents for her academic successes, but appeared resentful that her sister, whom she described as less academic than she was, was also rewarded, to make sure "she didn't feel left out":

*"It always seemed that whenever I did something well, sort of academically, even though I got rewarded, she'd get rewarded as well....it seemed that even when I did something good, she still got something good out of it too"*

There was also a strong sense of resentment from Jo when she explained how her sister's relationship problems have been seen to be prioritised by their mother over Jo's eating disorder:

*"Several appointments were made for me to come and see (therapist) with my mum...but there's always be something happening with (sister) so mum would have to pull out at the last minute...Mum would take the day off work to stay with her because she was so upset, so she never actually made it to an appointment".*

Jo also seems to feel this sense of resentment when describing how her sister is regarded by other members of their family:

*"I've never felt quite good enough for my gran....she makes a lot of fuss over (sister)...she wants to please her....and it seems, no matter what I do, I'm never good enough"*

Jo was also unhappy that she felt that the family had created some expectations about the types of girls she and her sister should be:

*"It's more acceptable that she's louder and she shouts, whereas when I do, it's not. Because I was always the little girl and she was the tomboy. So that loud behaviour's ok from her, but not from me."*

She also linked this to the age role she feels she was forced to accept, by being the eldest sister:

*“As the oldest, you’re expected to set a good example and the youngest is allowed to because they’re the youngest. Even now, when she’s sort of grown up, if you like, I’m still the oldest and I still have to set that good example...so, therefore, whenever I have a little slip, it’s really bad. But she can, you know, so what if she does something? She’s the youngest”.*

## **Sarah**

### **‘Being The Runt’**

Sarah has compared herself to her sisters and feels that she is “the unsettled one” in comparison. Her sisters both have long term relationships and children, and Sarah feels that they are not involved in conflict with their parents, while she describes many arguments between herself and her mother. She has feels that she is perceived as a failure because she left a successful career to retrain in the health service and believes that her parents have questioned this decision. She is also now living with her parents after a relationship broke down,

Sarah has one older and one younger sister. She views herself as the “typical middle child” and she believes she is the “odd one out”.

*“I’ve always been the disappointment, the one that they expected more from...I’ve always felt inferior to my other two sisters....I feel like I’ve let them down”.*



Sarah uses strong, negative language to describe herself throughout the interview, such as “runt”, “evil” and “nasty”:

*“I haven’t always been evil and nasty, it’s just something that’s developed in me I think”.*

She goes on to clarify that this negative language is a reflection of how she feels about herself:

*“I hate myself, most of the time”.*

She also believes that her younger sister shares the same view of her:

*“I think my youngest sister thinks I’m nasty, and I think that she thinks I’m selfish...because she’s openly said it”.*

She also believes that sharing her experiences of eating problems with her sisters might “help them to understand me a bit better” but she also worries that she is already seen as defective, and sharing any more problems would be too difficult:

*“I keep that bit away from them, that’s one bad thing about me they don’t need to know...I’ve got enough flaws, they don’t need to know this one as well”.*

The subtheme associated with this theme is that of ‘Being Ridiculous’. While ‘Being the Runt’ seems to be largely associated with her own interpretation of herself, ‘Being Ridiculous’ seems to be linked to the comments and opinions of her family:

*“To hear her tell me that I’m stupid, although she’s right, is not always something you want to hear”.*

Sarah and her youngest sister have had conversations about Sarah's exercise habits, which she believes her family see as "excessive". While her sisters do not know of Sarah's diagnosis, they have observed the length of time she spends at the gym, and her younger sister has discussed this with her:

*"She was saying it were ridiculous; I didn't need to work and exercise. I'd do a shift at work and go and do 5 hours in the gym. But I felt I had to go"*

Sarah's younger sister also commented that her gym sessions were unsuccessful, as well as "excessive":

*"She noticed the excessive exercise and she said, you know, you're exercising 5 hours a day in the gym, but you've not lost any weight, so obviously something's not working"*

Similarly:

*"There's no need for me to do the amount of exercise I do, it's ridiculous..I can do a double shift and then go for a swim after and I've got a bad hip at the moment, and they put it down to that, say I'm wearing my body out and I'm just being ridiculous".*

Sarah also talked about conversations with her mother which seemed linked to this theme:

*"She hit the roof over how many I was taking and she said that I was tapped in the head".*

#### 'Being Pushed Out'

Sarah appears to feel as though she is excluded from her family, though does not describe this as a deliberate process. Rather, she appears to feel that it is the result of her being “different” from her sisters and her mother. Here she is describing how she feels that she “knows” her sisters well, but that they do not know her:

*“From my point of view, I tend to know a lot about them..I know the ins and outs of my youngest sister’s life...and my eldest sister is quite an open book..From my own point of view, I don’t think they know me as well as they think they do. But that’s because I hold a lot back”.*

Later, she explains how she and her sisters used to exercise together, and shared that common interest, but now this no longer happens:

*“My youngest sister is pregnant, she can’t do it and my eldest sister’s always at work, so she doesn’t have time..but obviously, I’ve just gone to the extreme”.*

Sarah also describes how she sees herself as different from her sisters:

*“I’ve always gone for something completely different to my sisters. I don’t look like them, I look different. And I’m different natured to them. I feel more sensitive. Things upset me easier...and they don’t have a nasty streak in them like I have”.*

Later, she explicitly states her feeling of isolation from her family:

*"I feel like I'm.....on my own. Like maybe if they wanted to come to appointments with me or wanted to do things with me that maybe I'd be able to open up to them and tell them how things – or the situation I'm in now".*

Sarah also talked about her desire to have someone in her family that she could rely on:

*"Sometimes I wish someone was there for me to look up to and to ask for support and advice, I've sort of done everything on my own".*

Sarah explains that this feeling has been present since she was young:

*"I just got the feeling that sometimes I wasn't welcome. I always used to spend my weekend with my grandparents because, you know, I was welcome there"*

She also talked about how different she felt when she was a child:

*"I was separate to them. I was always the one wanting to be out with my friends, even in the snow, the rain. ....while everybody's sat inside watching telly or reading a book"*

Later, at the age of 13, Sarah went to live with her father, as a result of the conflict with her younger sister:

*"We were arguing that much I had to go and live with my dad...I'd always preferred my dad because I'm closer to my dad anyway. I felt like my dad actually enjoyed spending time with me, whereas my mum didn't. That's how I felt".*

This event may have been partly upsetting, at being asked to leave the family home, but could also have helped build some positive connections with her father, whom she perceived as closer to her. Unfortunately, her feelings of being pushed out were triggered again when her father left unexpectedly and Sarah was required to return to live with her mother and younger sister:

*"I lived with him, and then he disappeared. I came home from school one day and he'd gone. I went to live with my mum that night. That was something I didn't really want to do".*

Two years after his disappearance, Sarah's father returned and, despite never learning where he went, at 17 she was sent to live with him again:

*"Because my mum wasn't very well, I had to go live with my dad because me and my sister were bickering quite a lot. My mum couldn't cope. One of us had to go. And it was me".*

Returning to her father was a worrying experience for Sarah:

*"When you're 17 years old and you've already been rejected by your dad once, you don't really want to go down there again....it's always been there that he abandoned me, and would he do it again?"*

Sarah concluded by summarising her feelings of being pushed out of her family:

*"I don't think my family really know me at all. They think they do, but they don't".*

### 'Lost Identity'

To some degree, Sarah has struggled with her identity as being separate from her sisters (see journal paper results section), but she has also found it difficult to maintain her identity within the family. Sarah previously had a successful career, in which she was respected by her colleagues, and her mother also enjoyed this success. She was seen as the “clever” and “academic” sister. However, she has changed her career in the last 3 years and has had to re-train. This training has been difficult and, for the first time, she experienced failing an academic assignment. This appears to have been a challenge for her family to accept:

*“I did fail an assignment last year and they didn’t believe me and they were so disappointed that I’d failed and I’d never failed anything in my life and they didn’t believe me. I had to show them the results on paper, because they thought I was, you know, making it up”*

She also describes how she feels that her family do not understand who she really is:

*“I’ll do anything for them, but I always feel that they wouldn’t do that for me...I don’t know if they just think it’s because I’m tough and I’m strong and I don’t need anybody. I don’t know. But I’m not like that at all really”.*

And later, she expands on this:

*“I’ve had to help her with work because I’m the independent one, I’m the one that’s had the career in [XXX], I’m seen as the strong one, the clever one, but I’m not. But I’m seen as that”.*

Sarah also feels that her younger sister does not understand her identity:

*“That’s how she sees me, thinks that I’d love to get my mum into trouble, that I wouldn’t support my mum – but I wouldn’t at all”.*

Sarah believes that her sense of not being herself, or not knowing how to be herself, has had some impact on the eating problems she now experiences;

*“Sometimes I feel that if I’d been able to be myself around people, then maybe this would never have happened in the first place”*

In this next segment, Sarah appears to be questioning her interpretations of her experiences and her identity:

*“People say you’ve got middle child syndrome. I don’t know if I’ve just taken that on board too literally and believed everything people say about being a middle child – I don’t know”*

Sarah recalls a struggle to have her own identity as a child, with her sisters being dressed the same way and her youngest sister apparently trying to take on Sarah’s identity:

*“She used to steal my make up, my perfume, my deodorant, wear my clothes. Again, I had my – feel like my identity stolen really because she used to wear the things that I wore and stuff”*

#### ‘Longing for closeness’

This particular theme was a very small part of each of the stories of Amy, Sarah and Jo. While they were related to only one or two comments within the text, it was interesting that all three women seemed to share this experience. It has

been included here, in order to demonstrate that despite the problems they had experienced, they all appeared to want improved relationships with their sisters and hoped that this would happen in the future.

Amy hoped that her relationship with her sister would improve in the future and felt that a shared experience would help cement their relationship. She recalled a time when their mother's brother had an accident – their mutual concern for their mother was bonding:

*“And so me and (sister) were both worrying about mum, I think, and when you’ve got that common ground, although it’s awful, you know, we get on well, because we both understand that place. It’s just that we don’t share that common ground for eating issues and... and so that’s why in the distant, distant future, that if one of my parents did die then we’d probably be quite bound into relationship I suppose”*

Jo had a relationship with her sister characterised by intense conflict, yet she also wished for a closer relationship, and had made efforts to try to build bridges between them.

*“ But I suppose you do sort of look and think, well, why don’t I get on... yeah, I suppose I have. Like my best friend, she gets on really, really well with her older sister. And I suppose I have always wanted that, cause I will make a lot of effort. Like, I’ve, I’ve took the day off work this Saturday ‘cause it’s her birthday, and I’ve said I’ll take her out and everything, and do whatever she wants. And it does seem that I will put a lot of attention in”*



Despite feeling that these efforts are unreciprocated, she feels a continued need to build a relationship with her sister:

*“when she wants something she’ll be there, and then as soon as she doesn’t, she’ll be back to her normal self. But then, at the same time, she’s my sister and, erm, I’m gonna try and make it work”.*

Sarah also clearly articulated the feeling of wanting more closeness and a better relationship with her sisters. Though she does not describe qualitatively bad relationships with them, she wants more recognition and more sharing:

*“I’ve had sleepless nights by myself, no-one’s sat with me. No-one’s you know, supported me. No-one’s pushed me in the right direction, no-one’s written my assignment for me. Or helped me revise for any of my biology exams. I’ve done it all by myself”*

While all three wanted closeness and articulated their wishes for better bonding with their sisters, they all demonstrated some strengths within these relationships.

Amy described her relationship with her sister as “patchy”, by which she meant that they had progressed through many stages, and that they had periods of closeness:

*“it’s just progressed through so many different patches, so, maybe sometimes embarrassment but sometimes we were very close, in some years. Sometimes we used to go out drinking together and have a really good time”*

and

*"I don't know when I was, maybe seven to ten, erm, we were really quite close. Erm. Spent a lot of time playing games together"*

Jo's relationship was perhaps the most conflictual, but even here, there were good times together, as shown in this section of the interview:

*"Interviewer: How does it feel for you, when you, when you do have that time where you get on?"*

*Respondent: It's really nice - It's like everything's forgotten, if you like".*

Sarah's relationship with her elder sister was described as easy and straightforward, though perhaps somewhat distant, while her relationship with the younger sister was a little more complex. She believes this is because her older sister is "laid back" and her younger sister is "a warrior". However, she still states that:

*"I'm not jealous of them, anything like that. I don't feel bitter towards them. I love them both to bits. I'm always interested in their lives and I'll do anything for them. I've spent three hours at the hospital with my sister this morning because she didn't want to go on her own, and I'll do anything for either of them"*

### Extended Discussion

This study has investigated the experience of sibling relationships for three women with diagnosed eating disorders. Amy, Jo and Sarah were quite different in their age range, the age range of their siblings and their places in the birth order, so direct comparisons could not be made across their experiences.

However, there was some shared experience of being separate from their families. Amy talked of being “cut off”, while Jo and Sarah both felt “pushed out”. The reasons for these feelings were different for each of them, but the experience itself appeared powerful. It could be argued that having an eating disorder might create a distance between the self and others, but neither Jo nor Sarah felt disconnected from others outside their families. Jo was close to, and felt very supported by her boyfriend while Sarah described a group of friends who were very involved in her daily support and decision to seek therapy. Amy, in contrast, seemed detached from everyone. All three described their perceived distance from their families as pre-dating the development of their eating problems,. It would not be appropriate to draw any firm conclusions regarding the contribution this perceived distance may have had to the development of their eating problems as the sample is very small and the study was not intending to demonstrate any ‘causes’, however, it might be interesting to consider this question further in future research.

All three participants shared some experience of comparing themselves to their sisters, and perceiving that they did not fare well in this process. Amy and Sarah both felt that their sisters were ‘better’ in many ways; better daughters, better students, better sisters. Interestingly, Jo appeared to view her sister as the less good daughter but felt that their parents had the opposite view. Again, all three described this comparison process as being lifelong and, therefore, predating the development of eating problems.

How do these findings compare to those of sibling studies in other areas?

As discussed in the literature review, the relationship with, and influence of, siblings in other types of mental health problems have been closely studied. The areas receiving the most attention thus far appear to be schizophrenia, depression and ASD. I shall now discuss how these findings compare to results from those areas.

### Siblings and Schizophrenia

Within this field, again, the bulk of the literature has focussed on the perceptions of the relationship from the perspective of the unaffected sibling. There may be some methodological difficulties in assessing the sibling who has been diagnosed with schizophrenia, but it appears that this voice is absent from this literature as well. However, some of the studies which have looked at the relationship have made attempts to include the perspective of the 'unwell' sibling. For example, Smith & Greenberg (2008) investigated the quality of the relationships between siblings, using a measure of positive affect. This rated the perception of the 'unwell' sibling from the unaffected sibling's perspective and also asked them to rate their view of how their sibling perceived them. This may provide some measure of the quality of the relationship, but it is very difficult to assume that the unaffected sibling has a full understanding of how their 'unwell' sibling views them and feels toward them. They are also not clear whether the 'unwell' sibling perceived their siblings differently during times of recovery and times of experiencing symptoms. They also measured family cohesion, fear of the 'unwell' sibling, including any experiences of violence, personal gains obtained from the caring role, a measure of the siblings' attributions of control (i.e. whether they believed their 'unwell' sibling was in

control of their symptoms) and symptom frequency. Then, using multiple regression, they identified the predictors of sibling relationship quality. They found that better family cohesion and higher personal gains from caring predicted a higher relationship quality while experiences of violence, higher levels of fear and greater belief that their sibling could control their symptoms predicted a worse relationship quality. They concluded that sibling relationships needed increased understanding as they appeared to be a “major contributor” to the quality of life of adults with schizophrenia.

While Smith & Greenberg (2008) were not attempting to investigate the lived experience of the relationship, and did not ask the affected siblings for their perspectives, their work can be considered here. They found that siblings have a significant impact on the quality of life of the adult with schizophrenia, which appeared to be the case in this study as well. Amy, Jo and Sarah all described experiences with their siblings which could be interpreted as affecting the quality of their lives. Similarly, they found that the unaffected siblings held beliefs that the symptoms could be controlled by the ‘unwell’ sibling, and that the greater this belief was, the poorer the relationship overall. In this study, all three participants described their sisters’ efforts to ask them to moderate their exercise, eat more or eat more healthily. This might suggest that they too held the belief that their sisters could alter their behaviour if they wished.

They found that higher family cohesion was linked to better sibling relationships, which did not appear to be a feature of Amy, Jo and Sarah’s experiences. This study did not attempt to directly measure family cohesion, but all three

participants described their view that they had generally close families. They felt the other members were close, while they were excluded somehow.

It is not clear how easily the experiences of schizophrenia or eating disorders can be compared, though Treasure, Szumukler, Todd, Gavan & Joyce (2001) considered that they were comparable, as both conditions can be very long term, both can overwhelm the family, both can have severe consequences and both can lead to the individual 'changing' in sometimes significant ways, both physically and psychologically. Both are also associated with stigma from the wider community. Treasure *et al.*, (2001) found that the experience of caring for someone with an eating disorder actually had more negative consequences for the carer than caring for someone with psychosis.

#### Sibling relationships and depression

Shaw, Dallos & Shoebridge (2009) used IPA to investigate the experiences of six female adolescents who experienced depression. They found three superordinate themes: 'communication', 'hurt self' and 'difference'. While they did not directly structure their interviews around sibling relationships, all participants had siblings (though the actual numbers are not stated) and many of the quoted examples from their text included references to their relationships with their siblings. These were particularly notable in the 'communication' theme, in which participants described not knowing how to communicate with parents and siblings with whom they felt a lack of common interests. The 'hurt self' theme also encompassed their sibling relationships as they described feelings of being unwanted as compared to their siblings and that they did not have a defined identity within the family. The theme of 'difference' was

focussed mainly around their peers and no reference to siblings was made. However, it could be hypothesised that they may have felt different to their siblings if they, as stated, felt they did not share common ground with them and could not communicate with them.

This study is more easily compared to the Shaw, Dallos & Shoebridge (2009) study as it uses IPA to investigate the experiences of females (albeit younger females) and focuses on the individuals themselves, not their families. Both studies found participants felt unwanted and unlikeable. This is perhaps, unsurprising when studying any population of people with mental health problems. Indeed, it would be interesting to know how far these feelings spread into the 'healthy' or undiagnosed population. However, it is clear from the quotes provided that these were powerful feelings for both sets of participants. The age range of Shaw *et al's.*, study was 14 to 17 years old, which is younger than this study, and is a narrower band, so it is interesting to note such similar themes being identified. Interestingly, one of Shaw *et al's.*, participants also had a diagnosis of anorexia nervosa, and she also made reference to this being a protective part of her identity, as Amy did. None of the participants in this study had co-morbid diagnoses of depression alongside their eating disorder diagnoses though all three described episodes of very low mood.

#### Sibling relationships and Autistic Spectrum Disorder (ASD)

Petalas, Hastings, Nash, Dowey & Reilly (2009) used IPA to investigate the experiences of boys in middle childhood of their perceptions of their lives with their brothers who have been given a diagnosis of ASD. They found five themes: impact of their brother's condition on their lives, attitudes of others,

tolerance and acceptance towards their brothers, positive attitudes and experiences, and support for themselves and their brothers. Petalas *et al.*'s., study differs from the current one in that it focuses on children's experiences, has an all male sample and has taken the perspective of the sibling rather than the individual with ASD. However, they did find that ASD had significant impact upon the lives of the siblings and, like Smith & Greenberg (2008), they also found that the siblings were able to identify some positive aspects to their relationships,

#### How does the current study link to the literature regarding caring for people with eating disorders?

The research relating to caring for people with eating disorders has focussed on parents (Haigh & Treasure, 2003; Treasure *et al.*, 2001 & Whitney, Murray, Gavan, Todd, Whitaker & Treasure, 2005). All of these studies, however, have been conducted from the perspective of the carer. There may be a number of reasons for this, Firstly, it is useful to understand the burden of care across the range of different types of carer. Carers are often placed under considerable stress emotionally, financially and practically as they are required to adapt their lives around the needs of their relative with the eating disorder. It is also known that eating disorders create significant tension within the home as mealtimes become battles, concern for health increases and carers feel increasingly powerless. This could lead to carers developing their own mental health problems and requiring services. Haigh & Treasure (2003) felt that the carer burden was so significant that they developed a specific assessment tool to measure it routinely (CaNAM). It is also possible that there has been an



assumption that the individual with the eating disorder may not recall their relationships with carers very accurately. Extremely low body weight can lead to perceptual disturbances and cognitive problems and this could be part of the reason for neglecting the individual's own perspective for so long. However, it should not be argued that their perspectives are less valid. Amy, Jo and Sarah described very vividly their experiences and their feelings about their relationships with their sisters. The study was not seeking to find the 'truth' about those relationships and nor does it claim to have done so, but it has demonstrated that these three women had very significant interpretations of their relationships with their sisters and this appears to suggest that this perspective should be followed more closely in future research.

The studies of parents (Treasure *et al.*, 2001 & Whitney *et al.*, 2005) have used qualitative techniques to try to understand what it is like to be a parent of someone with an eating disorder. The findings tend to show that parents blame themselves and feel powerless to intervene (Whitney *et al.*, 2005) and that they suffer a significant burden of emotional distress (Treasure *et al.*, 2001). The current study showed some links with this. Amy talked at length about the damaging effect she felt she had upon her parents and the improvements she felt they had experienced since she moved out of the family home. She saw herself as toxic and damaging to their wellbeing. However, neither Jo nor Sarah made any reference to the impact they believed they had. One reason for this difference may be that Amy had been involved in considerable periods of family therapy and is likely to have heard directly, the effect her illness has had upon the family. Jo and Sarah both described their parents as unwilling to

discuss the eating disorder and, therefore, may have had less opportunity to hear their views.

### Limitations

This research may have been limited by some bias in the sample. While none of the criteria requested participants with particularly challenging sibling relationships, all who agreed to take part appeared to have quite complex and negative relationships with their sisters. It would have been interesting to see how the themes developed if some participants had experience of positive, affectionate sibling relationships. It is not known if people with eating disorders only have difficult sibling relationships, or whether this was an uncharacteristically skewed sample. Similarly, no attempt was made to recruit only women with sisters, but the sample happened to lack brothers. It is possible that different themes may have emerged with women who only had brothers. Schachter *et al's.*, (1976) theory of deidentification might suggest that the difference in gender would be sufficient to reduce competition. This could benefit from further study.

The stage of therapy for each participant was unmeasured, and the possible differences in therapeutic input might have led to differences in reflections on family dynamics. For example, Amy had been in lengthy individual therapy, hospital admission and family therapy while Sarah had only been diagnosed a few weeks before joining the study. This may have had an impact on the themes they raised.

As IPA is an experiential method, which aims to consider the interpretations of experiences, it is useful to consider how the researcher may have influenced analysis. My experience as a psychologist has prepared me for managing emotional distress and psychological difficulties, however, the field of eating disorders is not in my experience either professionally or personally. This was useful to the analytic process, as I did not have preconceived ideas regarding the client group. On the other hand, this could have been inhibitory during the interviews as somebody with a clinical background in eating disorders may have seen areas of discussion to follow more closely. I do, however, have my own experiences of sibling relationships. I have a brother, two years younger than myself whom I was brought up alongside. The majority of my play and social activities as a child, until my mid-teens, were conducted with him. We have been described by our mother as 'close', though this does not resemble my recall. We were in close proximity, but did not have significant emotional 'closeness'. My memories include significant feelings of being favoured by our father, while my brother was favoured by our mother. I am not aware of how my brother recalls this, as we have never discussed it. As adults we have very limited communication as we have little in common. This experience has influenced my thoughts regarding the nature of sibling relationships in that I am aware that they may be neither overwhelmingly positive nor negative, instead they may be neutral and detached. My relationship with my brother did not involve significant comparison, and I have wondered if this was due, at least in part, to our different genders.

## Conclusion

This study has used IPA to investigate the lived experiences of women with eating disorders and their siblings. Much of the relationship was perceived in a negative manner and the impact of sibling relationships on this client group appears to be significant and requires further investigation to develop a fuller understanding.

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## Extended Paper Appendices

### Appendix E1: Participant Information Sheet

*Positive about mental health and learning disability*



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#### **Women Under the Care of Eating Disorder Services and their Experiences of Sibling Relationships : A Phenomenological Perspective.**

##### **What is this study about?**

You have been invited to take part in this research study, which is about the experiences of adults with eating disorders and their brothers and sisters (siblings). There have not been many research studies into the relationships between people with eating disorders and their brothers and sisters. It is hoped that by starting to understand this in more detail we may be able to develop better ways of trying to help people with eating disorders, and their families.

##### **Why have I been asked to participate?**

You have been invited to take part because you are under the care of eating disorder treatment services and you have one or two brothers or sisters.

##### **What is the purpose of the study?**

This study is being conducted in order to try to understand the relationships that people with eating disorders have with their siblings. It is also a part of the course requirements for the Doctorate in Clinical Psychology. It may be published in a scientific journal when it is completed. In the written report for the course and any following journal articles, all participant information will be kept anonymous and no-one will be identifiable.

**Who is conducting the study?**

The study is being conducted by Jenny Smith, Trainee Clinical Psychologist from Lincoln University. Jenny has experience of talking to people about difficult or emotional topics and will conduct the interview sensitively. The study is being supervised by Dr Mark Gresswell at Lincoln University, and by Dr Katherine Huke from the Nottinghamshire Eating Disorder Service.

**Do I have to take part?**

No, you do not have to take part. This is voluntary and it will not affect any aspect of your care if you decide to take part, or decide not to take part. If you have any questions about deciding whether to take part or not, please contact the researcher, Jenny Smith, using the details provided at the end of this sheet.

**What will it involve?**

If you agree to take part in this study, the interviewer will contact you to arrange a convenient time to meet you for an interview. This will be either at your home or at the clinic where you normally attend for therapy and will depend on which option you would prefer. The interview will contain questions about your relationships with your siblings and will last approximately one hour. This can be made longer or shorter, as necessary.

**What are the possible disadvantages to me if I take part?**

If you decide to take part, you will be interviewed about your relationships with your brothers or sisters. For some people, this may involve talking about subjects that are difficult or upsetting. If this is too distressing, you can end the interview at any time. You can also discuss any concerns you may have about the interview with your clinician, the researcher or the researcher's academic supervisor (contact details given below).

**What are the possible benefits to me?**

It is possible that you may not have talked about this area of your life before. This may help you to think about new topics you might want to take to your therapy sessions. However, the study will not have any direct benefits to participants, but may help in the development of future ideas about treatment.

**What information will be collected?**

The interview will be tape recorded anonymously, with a participant number, not your name. The tapes will then be transcribed later. Audio tapes will be destroyed following the study. The written transcripts will also be anonymous and stored securely. The interviews and transcripts will be kept confidential and not discussed with anyone outside the immediate

research team, except for research supervision. The only time any information may be passed on would be if you or anyone around you appeared to be at risk of significant harm. In this case, the interviewer would encourage you to discuss this with your clinician and might pass the information onto your clinician directly.

**Will it have any effect on the care I receive?**

No. Whether you decide to participate or not, there will be no effect on the treatment you receive from your care team. This research study is not a part of your treatment and is, therefore, entirely voluntary.

**If I agree to take part, can I change my mind later?**

Yes, you can agree and then change your mind. If you change your mind, even after the interview has taken place, your data will be withdrawn from the study and tapes and transcripts will be destroyed. However, once the study has been written up, it will not be possible to remove your data.

**Will my information be kept confidential and secure?**

Yes, information will be kept confidential and secure. All tapes will be destroyed once they have been transcribed and written transcripts will be anonymous. These will then be stored securely at the University, in a locked cabinet. However, if you mention anything in the interview which suggests there is a risk of harm to you or someone else, the interviewer will have a duty to pass this information on to your clinician.

**What happens when the research stops?**

The study will be completed and written into a report for the University. Nobody will be identifiable from information contained in this report. The transcripts of tapes will be stored securely at the University of Lincoln for 7 years. This is in line with University guidelines.

**What do I do if I feel upset during or after the interview?**

If you feel upset about anything that you talk about in the interview, you can tell the interviewer how you are feeling. The interview can be paused while you take a break, or you can ask to stop the interview completely. If the interview is stopped, you won't have to continue if you don't want to. If you feel upset during or after the interview, you should talk to your clinician about it, during your next scheduled session.

**What do I do if I have any complaints about this study?**

If you have any complaints about the researcher, or about how the research was carried out, you can contact the academic supervisor, Dr Mark Gresswell, using the contact information given at the end of this sheet.

**Who has reviewed this study design and procedures?**

The plan of the study has been reviewed by the academic supervisor and the clinical supervisor. The research proposal and plan of investigation have also been reviewed by a Research Ethics Committee (REC), to ensure that participants are not put at risk.

**Who do I contact if I have any more questions about this study?**

If you have any questions about this study, please do not hesitate to contact the researcher, Jenny Smith, or Dr Mark Gresswell, academic supervisor.

Thank you for reading this information.

**Contact Details:**

**Jenny Smith**, Trainee Clinical Psychologist, can be contacted at the Trent Doctorate in Clinical Psychology, University of Lincoln, on 01522 886029. E-mail: [058044250@students.lincoln.ac.uk](mailto:058044250@students.lincoln.ac.uk)

**Dr Mark Gresswell**, Deputy Course Director and academic supervisor, can also be contacted at the Trent Doctorate in Clinical Psychology, University of Lincoln, on 01522 886029. E-mail: [mgresswell@lincoln.ac.uk](mailto:mgresswell@lincoln.ac.uk)

## Appendix E2: Consent Form

*Positive about mental health and learning disability*



Centre Number:  
Study Number:  
Patient Identification Number for this trial:

### **CONSENT FORM**

#### **Women Under the Care of Eating Disorder Services and their Experiences of Sibling Relationships : A Phenomenological Perspective.**

Name of Researcher: Jenny Smith

This consent form is for the study outlined in the Participant Information Sheet. It is a study about the experience of relationships with brothers and sisters, from the perspective of someone under the care of an eating disorder service. It will involve meeting the researcher for one interview, to talk about your experiences of your relationships with your brothers and sisters.

If you would like to participate in this study, please read this consent form and answer the following questions. When you have done so, please sign and print your name where indicated.

Please initial box

1. I confirm that I have read and understand the information sheet dated 20.01.2010 (version 4) for the above study. I have had the opportunity to

☐

consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I agree to my GP being informed of my participation in the study ☐
5. I agree to take part in the above study. ☐

_____	_____	_____
<b>Name of Patient</b>	<b>Date</b>	<b>Signature</b>
_____	_____	_____
Name of Person taking consent	Date	Signature
(if different from researcher)		
_____	_____	_____
Researcher	Date	Signature

When completed, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes

## Appendix E3: Inclusion / Exclusion criteria provided to clinicians

### **“How do women under the care of eating disorders services experience sibling relationships? A phenomenological perspective”**

Thank you for considering referring some of your clients to this study. The criteria for inclusion and exclusion are as follows:

#### **Inclusion Criteria**

1. Female
2. Aged between 18 and 30
3. Have 1 or 2 siblings (siblings can be male or female, full siblings, step siblings or half siblings – but they must have lived with the participant at some point)
4. Under the care of NEDS or Freed

#### **Exclusion Criteria**

1. Unable to provide informed consent – eg. Cognitive impairment, acute emotional distress, psychotic phenomena

If you have any clients who fit these criteria, please consider referring them to the study. The procedure would be as follows:

1. Identify suitable individual
2. Discuss study with the individual – if they are interested:
3. Explain Information Sheet
4. Give Participant Pack
5. Ask for consent to be signed and returned to me in the enclosed prepaid envelope

Once I have received the consent form, I will contact you to state this has been received and obtain contact number for participant, to arrange interview. I will also inform you of:

1. Date & time of interview
2. Any concerns arising from interview

Once the study has been completed, I will come back to the service to feedback the results and discuss with the team.

Thanks again for your assistance.



#### Appendix E4: Statement of introduction for clinicians

“I would like to discuss a research project with you. A trainee clinical psychologist is undertaking her research project with our service and I would like to talk to you about the possibility of you participating. The study is about women involved with eating disorder services (or ‘women with eating disorders’) and their relationships with their brothers and sisters (or siblings). We know that family relationships are important to people with eating disorders but we don’t yet know much about the importance of relationships with brothers and sisters. The study will involve an interview with the researcher, which will last about an hour. The interview will cover topics relating to your relationships with your brothers and sisters. You will not be under any pressure to discuss any issues you would rather not discuss, and you would be able to change your mind at any time.

Would you be willing to consider participating in this study? Do you have any questions?”

Please provide the participant pack and explain they can contact me by phone or e-mail to ask any questions that you feel unable to answer.

### Appendix E5: Participant contact details form

Please indicate below how you would prefer to be contacted (e.g. phone or e-mail) and provide details so I can contact you to arrange the interview.

Please place this in the self-addressed envelope provided, along with your consent form.

Many thanks for your participation.

## Appendix E6: Interview Schedule

**The process of the interview:**

Introduce the interview – “Some of the research around eating disorders has looked at people’s family experiences. However, this has focussed mainly on relationships with parents. This study is looking into experiences of relationships with brothers and sisters. Today I would like to talk to you about your own experiences of your relationships with your brothers and sisters. Is there anything you would like to ask before we continue?”

### Demographics:

Participant number etc)	Residential status (i.e. with family, partner, friends etc)
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Age Ethnicity

### History:

How many brothers and/or sisters do you have? (Specify numbers of each & whether step, half or full siblings))

How old are they? – Older or younger than you?

Do you live with them now? – How long for?

Have you ever lived with them? – How long for?

Do you see them regularly? – How often? What for? Who instigates this?

Do they know about your eating disorder? – How do they know? How long have they known?  
How did you feel about them knowing?

### Experiences:

What was your relationship like growing up?

How has it been since then?

Tell me about your relationship with them now?

How do you experience it?

How does it feel?

How has it been since the eating disorder became known?

**Close:**

Is there anything else that you would like to tell me about or that you feel is relevant to your relationship with your brothers and sisters?

Is there anything from today that you might want to take back to therapy sessions?

## Appendix E7: Confidentiality statement – transcriber

APPENDIX C15

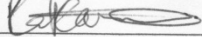
### **Confidentiality Agreement for Transcribers**

I, Paula Pearce, transcriber, agree to maintain full confidentiality in regards to any and all audiotapes/audio-files and documentation received from Jennifer Smith related to her doctoral study on sibling relationships and eating disorders. Furthermore, I agree:

1. To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the transcription of audio-taped interviews, or in any associated documents;
2. To not make copies of any audiotapes/audio-files or computerized files of the transcribed interview texts, unless specifically requested to do so by Jennifer Smith;
3. To store all study-related audiotapes and materials in a safe, secure location as long as they are in my possession;
4. To return all audiotapes/audio-files and study-related documents to Jennifer Smith in a complete and timely manner.
5. To delete all electronic files containing study-related documents from my computer hard drive and any backup devices.

I am aware that I can be held legally liable for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the audiotapes and/or files to which I will have access.

Transcriber's name (printed) PAULA PEARCE

Transcriber's signature 

Date 28/7/10

## Appendix E8: Extract from transcript of Interview 1, with notes

Text in italics can be followed from this interview stage, to the development of superordinate themes (Appendix E9).

Uncertainty Patchiness	Jennie Smith: And is it alright to use her name? Are you happy to tell me her name? Participant 01: Yeah, it's Louise. Jennie Smith: And is she a full sister or a step sister or? Participant 01: Full, yeah, she's 18 months older, than me. Jennie Smith: Okay. So you're not living with her now? Participant 01: No. Jennie Smith: How long has it been since you lived with her? Participant 01: Quite a while, erm. She went to university, probably about 2002, something like that. I don't know what the numbers are, it's several years, erm, and she used to come back for summer holidays so I was there then, if that counts, for a couple of months at a time, erm. And then she moved down to London probably two or three years ago, erm, kind of officially if you know what I mean, so I was still at home then. So let's say three years since we've been actually living together, in a formal sense. Erm, but there was quite big patches of holiday when we would be still in the same house, if that makes sense (apologetic laugh).	Anxiety in voice and body lang. Playing with clothes and hair. Uncertainty re: how long sister has been away.
Sharing Space – physical space		Patchiness. Sharing physical space – same house.
Confusion over home		
Patchiness		
Confusion over home	Jennie Smith: Sure. So do you see much of her now? Participant 01: Erm. When we get together as a family, and she calls home, but we have kind of settled into a... you know, her home is London now, so us both going home is the same. It's not... it's quite hard to explain. Erm. Yeah, I think we've just got different bases now. And some... Yeah, that's quite complicated really. Like I don't know if, you have a family but you know there's kind of a presumption that when one person visits home that the other one will too because it'll be like a little reunited thing, it's kind of like that.	Confused sentences – hesitation? Uncertainty? Not understanding herself? Is going home the same for both of them? Concept of family Confusion over where home is Expectations from others
Expectations from others Presumptions		
Reunions	Jennie Smith: So is that when she goes home then you feel the need to go back as well? Participant 01: Yeah. When she goes home it's probably expected that I would go home. Even though I'm two miles away and she's 200 it doesn't really make much difference. Jennie Smith: How does that feel?	Expectations from others or self? To whom does it make no difference? Is she expected to change her plans for others?
Family expect / demand things		

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<p>Incomplete language Contradictions in language</p> <p>Changing relationship with sister</p> <p>Hostility</p> <p>Self blame Responsibility to make others happy</p> <p>Power imbalance in the relationship</p> <p>Contradictions in language</p> <p>Looking for sisters perspective</p> <p>Claiming to be happy Presenting positive image</p> <p>Equality in relationships</p> <p>Resentment</p> <p>Sadness / loss/ grief</p> <p>Need to protect others</p> <p>Damage she does to others</p> <p>Guilt</p> <p>Control</p> <p>Sisters need to protect family</p>	<p>Participant 01:</p> <p>Jennie Smith: Participant 01:</p> <p>Jennie Smith: Participant 01:</p> <p>Jennie Smith: Participant 01:</p>	<p>It's usually quite tense, but me and Louise were really, really... we were really close, and things have kind of, the dynamics of things have changed, so... I'm sure we have the capacity to be really close, like we get on very well, but erm... I think just the way that things have been have sent her... well, you know, there's a lot of hostilities between us so we don't... it's tense basically (laughing). We probably get on better when it's just me and her rather than being in that family setting, I think.</p> <p>What influences that do you think? Erm. How long she's been with me, in hours. How many meals we've passed over during that time. Everything really, dynamics. Things she's picking up off my parents, things that I'm doing. She doesn't really like to hear things that aren't so good. She says, 'How are you?' And I say, 'Yeah, alright.' She gets this kind of like anxious look on her face like, 'Yeah?' It's just... yeah it's just like that, 'Yeah?' (laugh of annoyance) You know, she doesn't want to hear, 'It's not so good,' she wants to hear, 'Yeah, things are really good.'</p> <p>Yeah.</p> <p>But then she'll say... you know, I can still talk to her and stuff. Things aren't that good. Yeah, it's quite contradictory. Um. She wants to know that things are okay for her own reassurance I think. So I'm happy to just say that things are, really, regardless.</p> <p>And how does that feel from your point of view?</p> <p>Erm. I don't think we have a very equal relationship anymore. Which is very sad, I think. But I feel there's something I should protect her from. I feel kind of resentful that I have to protect her from it because she's... erm, she's a bit funny about health things, she gets quite neurotic. A sort of hypochondriac, I think. And she feels resentful to me because I've damaged the family I think, a bit. So she says, 'It's not you really I'm worried about anymore, you know, it's... I'm just worried about mum and dad and the effect it has on them' and... 'Dad's got high blood pressure' and... So I suppose if it wasn't all in that family setting then maybe it would be easier. But it is, that's the way it is.</p>	<p>Why tense? Emphasis on 'really really'</p> <p>Lots of unfinished thoughts, discomfort expressing negative thoughts about sister?</p> <p>Why did dynamics change?</p> <p>Who changed them? Between us – impersonal Contradictory ideas?</p> <p>Language – self blaming,</p> <p>Power? Responsibility to keep others happy?</p> <p>Sarcasm – voice</p> <p>Consideration of sister's perspective?</p> <p>Sense of concern from sister, that isn't acknowledged.</p> <p>Contradictions – in own language and in sisters language and approach. Sense of sisters perspective?</p> <p>Is she happy? Didn't sound like it – voice did not match. Avoiding real feelings here?</p> <p>Should this r'ship be equal? Was it ever equal? Age, power etc. What does equal mean?</p> <p>Need to protect others – from herself? Distress?</p> <p>Resentment of feeling. Resentment of sister? Labelling sister. Includes sisters views</p> <p>Using more complete sentences</p> <p>Guilt, shame, power, control? (damage) Do others think the same of her? Strong statement. Family making things more</p>
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	Jennie Smith: So you said that the relationship wasn't equal anymore	difficult
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ED as a skill / identity Academic identity	Participant 01: Participant 01:	No. Jennie Smith: When did that change? Do you remember? Erm. A long time ago really. Erm... We've always been very different. But we're kind of... erm. I've been quite, gone down the artistic-ish route, you know, Englishy stuff, and she's gone down the business route, erm, into London and I suppose there was times when my academic success was more... You know, it had the potential to make things unequal, because she's never been that academic. Always found that quite difficult. But we've made up for things in that... Kind of balance things out, don't they? You know. Artsy girl, sciency girl. Erm. So we were in balance sort of then, but then, when I had quite a severe eating disorder, and she was quite healthy, it still stayed in balance because I had something and she had something. I don't know if that makes sense.	Difference in academic skills Sense of difference?
Balance – consciously controlled Balance vs difference		When you say you had something are you referring to the eating disorder?	Sister actually has 2 degrees and good job – why is that not academic?
Competition – academic	Jennie Smith: Participant 01:	Yeah. It was like... I don't think eating disorders are a problem that necessarily make you inferior. (Pause) It's probably not a very good example but if someone had a physical problem, like, let's say they were incontinent, that's a sort of... That problem is potentially going to make you not an equal, like sink a bit. That kind of illness, might have the potential to make you pitied. But eating disorders seem to have this kind of... a bit of respect because people don't really understand much about them. I mean, I don't think people pity eating disorder patients as much. Or maybe this is just what I feel, but I feel that there is a kind of view that maybe you're a bit arrogant, and vain. Which I probably am.	Balance and difference – dichotomy  ED as a skill or an identity ED vs successful sister
Pity vs respect Comparisons with other illnesses	Jennie Smith: Participant 01:	Do you experience that in your relationship with your sister? Erm. (Pause) I don't really know if that's there. (Pause) Yeah. That's really hard to answer that. (Pause) I suppose I just mean that... when... when I was very ill, I suppose, it was almost a problem that was being worked out, it required a lot of attention, it was quite an important thing, and... And so I suppose I had a sense of having quite a lot, in time, and attention, and... Erm. And she	Power – inferiority / superiority  Pity as undesirable vs respect. Comparisons with physical illness
ED brings respect Self as arrogant / vain	Jennie Smith: Participant 01:		Sense of pride in ED  Something special about her because ED is so complicated. View of self Why choose incontinence?
Self as a problem to be solved			Question unclear
Need for attention Important because of ED			Attention, being important, being worked out.
Strength			What its like to be her sister – had to give up attention and be strong  Like having a skill or training –



ED is a skill with something to show for it	had to be the stronger one. And that's kind of the case now, but because I don't really have the eating disorder, or I don't feel like I have anything to show for it,	what did she want to show for it? Like an achievement.
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<p>Direct comparison with sister</p> <p>ED as protection against comparison</p> <p>Judgement about life success</p> <p>Contradictions</p> <p>Comparison is bad</p> <p>Possession – clothes, friends, academia.</p> <p>Ownership</p> <p>Conflict/ Anger</p> <p>Being similar is a threat</p> <p>Jealousy?</p> <p>Need for reassurance</p> <p>Time spent thinking about the relationship</p> <p>Difference vs sameness – need for separation</p> <p>Self criticism</p> <p>Deliberate separation</p> <p>Competition is tiring</p>	<p>now she's the one who's... you know, I'm at a lower level in the kind of, you know, life success thing. I'm 24 and I live in my flat, and I don't have a job, and I haven't finished my university degree. And she's in London, she's done two degrees, she's got a very long-term boyfriend in a flat, and she's only... she's 25, it's kind of... Without an eating disorder in the picture you're kind of compared a bit, on a level.</p> <p>Jennie Smith: Participant 01:</p> <p>Do you compare yourselves? Erm, yeah, I think we do. I think we'd probably both say now that... no, we know that's a completely redundant thing to do, and there's no comparison because we're so different. <i>But the fact is that, you know, we've always compared each other, and...</i> You know, I used to get really angry if she bought any clothing that was similar to mine, because we had quite distinctive styles and it's just kind of... I don't know if it's jealousy, like kind of a possessiveness about what we look like and who we are and who we're friends with, and couldn't really be friends with the same friends. It was just kind of life, I think there's a lot of strange feelings of possession around things. She was good at netball so if I was good at netball that would be an enormous threat, so I'd have to choose something different. It sounds a bit odd, doesn't it?</p> <p>Jennie Smith: Participant 01:</p> <p>It sounds like it was difficult to separate yourself out in some way. Yeah. Or not difficult, we presumed that it happened automatically. That when people say, 'Oh, you're very different,' I sometimes wonder if perhaps we made it that way, a bit. And that if we'd made quite decisive... or taking quite decisive actions. I always use really rubbishy examples, but if I'd tried really hard at the sciences and she'd tried really hard at English then maybe we could have just taken up different positions. <i>I wonder how much we tried to make ourselves have complete different corners.</i></p> <p>Jennie Smith:</p> <p>Why do you think you might have done that?</p>	<p>Now she's the one who.. has this changed? Did things used to be different?</p> <p>Comparisons of outcomes – life success</p> <p>ED is a protection against comparison and a reason for lack of success.</p> <p>Contradiction of self – uncertainty?</p> <p>Embarrassment?</p> <p>Completely redundant – rejection of validity of comparison</p> <p>Do they compare themselves or do others do it? Have they been told they're different?</p> <p>Conflict over these areas?</p> <p>Threat, jealousy, possessiveness, ownership, control?</p> <p>Possession of people, pastimes, clothes, academia</p> <p>'have to choose' – who insisted on this? Needed reassurance?</p> <p>Has thought about this relationship</p> <p>Self deprecating language.</p> <p>Mutual decision to be different – why would this have been needed? Did they both try to be different?</p>
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	Participant 01:  Jennie Smith:	Erm. <i>Because it's very hard work being in competition all the time, isn't it?</i> So if you're completely different from each other then you don't have to compete?	If they're the same, they have to compete – no alternative. Assumption that this is the case. Seeking reassurance?
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Metaphorical comparisons to 2 talented women	Participant 01:	Yeah, or we're competing in such different things. Because I think in metaphors it does make it quite difficult because I'm always talking... having translated it into... So this will probably all sound really stupid, but if... You know the Williams sisters?	Competition again.
Need for permission to be good at the same thing	Jennie Smith:	(Indicates agreement)	
Comparison is ok if separate people	Participant 01:	<i>If one of those played football and one placed tennis then they could both be very, very good, and you might compare them, but you'd be comparing them on their different fields, so they wouldn't be like the same common denominator or whatever it would be.</i>	Uncertainty and self doubt.
	Jennie Smith:	Yes.	Permission to both be very good – not normally allowed.
	Participant 01:	(Pause) I can't remember what the question was now.	Being compared is ok if you're different.
	Jennie Smith:	I think you were talking about being compared and why you felt the need to be different.	SCD – is she separate from her sister?
Permission to be separate people	Participant 01:	Yeah.	
Comparison is threatening and intense	Jennie Smith:	I guess with that Williams sisters metaphor, the idea of them being in different fields would have meant that people could have seen them both as separately excellent, but because they're both in tennis there is an inherent comparison over which one's better than the other one at that particular thing.	Inherent – inevitable, unavoidable
			This is threatening. It would be bad to be the less good one.
Head to head = combat	Participant 01:	Yeah. And they are head to head competition rather than, you know, having two different criteria. Erm.	Intense and threatening. Different people?
	Jennie Smith:	So is that how it felt with you and your sister?	
Ownership of own fields	Participant 01:	Yeah. <i>We had different sports, in a metaphorical sense, and we still do now. Erm. And I would always say, 'Woah, no, I don't want to go into business, I never would want to go into it,' but the fact is that I, whatever I wanted I couldn't because that's her corner, and it would be very, very threatening to... you know, to go there.</i> Which obviously I wouldn't. It's not physically or feasibly... you know. Erm. (Pause) Yeah. But the whole thing about comparing, yes, we still do compare an awful lot I think. But probably me more than her, because I feel a bit inferior.	Is this a pretence? An act to cover resentment?
Physical diminishment and frailty			Belonging / ownership
Comparisons Inferiority			Sister owns business field – what else does she own? Friends, family? Threatening for who?
			Language is flat – doesn't convey depth of feeling Physical unsuitability for business? Why? More than a bit inferior.

Appendix E9: Superordinate themes from Interview 1, provided as an example of the process of theme identification

Superordinate theme	Themes from interview	Quotes
1. Seeking Balance	Power Imbalance Equality in relationships ED as a skill ED as identity Achievement from ED ED as protection against comparison Competition Comparisons Balance vs Difference Inferiority Comparison as threat Deliberate separation	<p>"now she's the one who's, you know, i'm at a lower level in the kind of, you know, life success thing. I'm 24 and I live in my flat and I don't have a job and I haven't finished my university degree. And she's in London, she's done 2 degrees. She's got a very long term boyfriend in a flat and she's only..she's 25, it's kind of..."</p> <p>"Kind of balance things out don't they? You know, artsy girl, sciency girl, so we were in balance sort of, then, But then, when I had quite a severe eating disorder, and she was quite healthy, it still stayed in balance because I had something and she had something"</p> <p>"We've always compared each other, and..you know, I used to get really angry if she bought any clothing that was similar to mine because we had quite distinctive styles....i don't know if it's jealousy, like kind of a possessiveness about what we look like and who we are, and who we're friends with.....she was good at netball, so if I was good at netball that would be an enormous threat, so I'd have to choose something different...I wonder how much we tried to make ourselves have completely different corners".</p>

<p>2.</p> <p>Being Bad</p>	<p>Self as unlikeable</p> <p>Self as problem</p> <p>Self blame</p> <p>Self as toxic</p> <p>Guilt and shame</p> <p>ED as disgusting</p>	<p>“Because they’re happier, and I see that they’re happier. Well, everyone does really...and that’s because I’m not there, so that’s a good thing really”</p> <p>“You know, they’ve turned into one of those really nice couples. And that’s because I’m not there, so that’s a good thing”</p> <p>“It’s just kind of sad that all of this has got in the way and that, therefore, I’m to blame for it”</p> <p>“She told me I looked awful, and she told me I was rather disgusting and selfish, and why didn’t I think about the parents...she doesn’t always word things very well, but at least she’s honest”</p>
<p>3.</p> <p>I don’t correlate</p>	<p>Not belonging</p> <p>Difference from family</p> <p>Being inhuman</p> <p>Otherworldly</p> <p>Being cut off</p> <p>Physical distance</p> <p>Emotionally cut off</p>	<p>“She wanted me back in the real world, which I had departed I think”</p> <p>“I didn’t have particularly great friends at school, and I wasn’t particularly sociable”</p> <p>“Maybe some point around 13, I’d left kind of human reality..and after that I was in this unfamiliar place of using food and drinking”</p> <p>“When she says ‘how are you?’ and I say ‘I’m fine’..if I said ‘well, no, actually, things aren’t that great’, she’d be kind of like ‘oh, why?’ There’d be this moment of anxiety, and it would just be the thought of trying to explain so much stuff, and how things feel and what it’s like..they’re cans of worms. So I say ‘no, no, things are good’”.</p>

## Appendix E10: Excerpt from reflective journal

This was completed following an interview.

08.07.2010	<u>Personal Reflections following interview 1</u>
Thoughts	<p>She appeared anxious – body language, tone of voice. Hair twirling, fiddling with a scarf and her fingers. Seemed eager to help. She seemed happy to talk about all the issues – I spoke less than I expected to.</p>
Feelings	<p>I felt a degree of responsibility for her and guilt that I was eliciting her experiences without offering any therapeutic intervention. Sought clinical supervision following the interview to discuss this. She appeared vulnerable – due to her body language, quiet voice and physical size. I felt a sense of being angry with her family, and needed to remind myself that we were discussing her perceptions of her relationships. Again, this was discussed in supervision too.</p>
Thoughts on schedule	<p>Questions worked well. Sufficient focus to keep on topic of sibling relationship, but a high degree of freedom for the participant to manage the direction. She was very articulate, so it is possible that further interviews will need more guidance. <u>Plan: to think about prompts – these worked well here, but may need more in future.</u></p>
Theories:	<p>My assumptions from this interview are that comparison, identity and competition will emerge from the text. I left with a sense that this relationship was characterised by two young women who don't know how they are different, so they are trying to do everything they can to highlight their separateness. The eating disorder seems very important to P1 as she gets a sense of identity and achievement from it. Real ambivalence about letting it go. Who is she without it?</p>